FACTORS INFLUENCING THE IMPACT OF PRIMARY AND SECONDARY PREVENTION STRATEGIES FOR CERVICAL CANCER AMONG QUEENSLAND WOMEN

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Abstract

Since the introduction of the National Human Papillomavirus Vaccine Program (NHPVP) in 2007, few studies have assessed women's knowledge, beliefs and attitudes towards cervical screening and human papillomavirus (HPV) vaccination in Australia. It is imperative to ascertain this, as substantial changes are anticipated to the National Cervical Screening Program (NCSP) through a process called 'the Renewal', to ensure any changes that are introduced will be acceptable and well understood by women.

The objectives of this study were to describe Queensland women's current knowledge of cervical cancer/screening and HPV, their beliefs and attitudes towards Pap smears and the HPV vaccine and seek their advice on effective methods for communicating changes to the NCSP in their communities. This research was a descriptive-exploratory study that incorporated a combination of qualitative and quantitative methods within the context of the Health Belief Model (HBM). A computer-assisted telephone interview (CATI) survey of 1002 Queensland women was conducted in Phase 1 of the study. During Phase 2 of the study, 23 focus groups were conducted throughout Queensland to gather in-depth information about women's knowledge, awareness and acceptance about cervical cancer prevention strategies.

This study found high levels of awareness of HPV (over 60%) and the HPV vaccine (over 86%) amongst Queensland women. However, it also identified considerable uncertainty amongst participants about perceived susceptibility to cervical cancer, especially, the link between cervical cancer, HPV and sexual activity. Women also had limited understanding of the benefit of the Pap smear as a preventative strategy, with many women thinking the main purpose of the Pap smear was for the early detection of cancer. Despite high awareness of HPV, women participating in this study also had significant knowledge deficits about their susceptibility to HPV and the severity of HPV infection. Queensland women had high levels of awareness of the HPV vaccine, which was most commonly via the media. High acceptance of the HPV vaccine was found amongst participants although awareness of the full benefits of vaccination was not evident with little

acknowledgement that the quadrivalent vaccine used in the NHPVP would also prevent genital warts.

Extensive barriers to having Pap smears, including physical and psychological discomfort, were identified and the most common barriers to vaccination were concerns about side effects and a lack of information upon which to make a decision about consent. Women described enablers for screening participation, such as reminder systems and practitioner characteristics, and expressed positive views towards self collected testing as an enabler, particularly for women who did not attend screening.

As this study was conducted with Queensland women it may therefore not be representative of women from other parts of Australia and as participants were more likely to report they were regular screeners than Queensland women overall, these results may not be representative of women least likely to participate in cervical screening. The use of self-reported cervical screening history may also have led to over-reporting of screening status and previous abnormalities by participants. This study reveals significant gaps in Queensland women's knowledge that require effective communication strategies to address. Recommendations from this study highlight the need for increased community education to raise awareness about primary and secondary cervical cancer prevention strategies, training of cervical screening providers in sensitive examination techniques, a reduction in costs associated with screening, the exploration of alternative service models and communication plans that incorporate methods women trust and recommend for disseminating information about changes to the NCSP.

This study is the first large study to explore women's perceptions of the Pap smear and barriers to screening, their knowledge about HPV and their attitudes towards the HPV vaccine in Queensland, since the introduction of the NHPVP. It highlights considerable uncertainty about many aspects of cervical cancer and primary and secondary prevention strategies available in Australia and identified many barriers to cervical screening and concerns about HPV vaccination. These knowledge gaps and barriers need to be taken into account and addressed within the context of anticipated changes to the NCSP to ensure benefits are maximised for women in future primary and secondary cervical cancer prevention strategies in the Australian context.

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List of Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ASR	Age standardised rate
CATI	Computer assisted telephone interview
CSSB/CSSU	Cancer Screening Services Branch/Unit
Cx	Cervical
DNA	Deoxyribonucleic acid
HBM	Health Belief Model
HPV	Human papillomavirus
NCIRS	National Centre for Immunisation Research and Surveillance
NCSP	National Cervical Screening Program
NHPVP	National Human Papillomavirus Vaccination Program
NHPVR	National HPV Vaccination Register
OR	Odds ratio
Pap smear	Papanicolaou smear
PSR	Queensland Health Pap Smear Register
PVE	Pelvic Examination (per vaginal examination)
QCR	Queensland Cancer Registry
QCSP	Queensland Cervical Screening Program
QCWA	Queensland Country Women's Association
QUT	Queensland University of Technology
SEIFA	Socio-economic indexes for areas
SES	Socio-economic status
WHO	World Health Organisation

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: QUT Verified Signature

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Chapter 1: Introduction

Background information relevant to this thesis is described in the first section (Section 1.1) of this chapter followed by the context of this study (Section 1.2), and the rationale for undertaking this research (Section 1.3). In Section 1.4 the significance and scope of this research is described and the remaining chapters of the thesis are outlined in Section 1.5.

1.1 BACKGROUND

Australia has the second lowest rate of cervical cancer in the world, which has largely been attributed to the introduction of an organised approach to cervical screening in 1991, known as the National Cervical Screening Program (NCSP). The NCSP is a secondary prevention program based on a screening policy that has remained unchanged for 20 years, and promotes eligible women to have two yearly Pap smears to screen for precancerous epithelial abnormalities, which can be treated before cancer develops (Tomatis and Huff, 2001). Since the introduction of the NCSP in 1991, cervical cancer incidence and mortality rates have more than halved in Australia demonstrating the success of the NCSP as a public health intervention (AIHW, 2011).

Up to 90% of squamous cell carcinoma of the cervix can be prevented through regular participation in cervical screening (Hakama, Miller and Day, 1986). In Australia in 2008/09, more than 58.6% of women participated in two yearly cervical screening as recommended by the NCSP (AIHW, 2011). Women who do not participate regularly in the screening program are more likely to be diagnosed with cervical cancer. More than 81% of women diagnosed with squamous cell carcinoma in Queensland in 2008 had not been screened for more than four years prior to their diagnosis (CSSB, 2011). Aboriginal and Torres Strait Islander women are more likely to be diagnosed with or die from cervical cancer than non-Indigenous women, which is largely attributed to their lower rates of screening participation (AIHW, 2011. 2007. 2005b; Homewood, Coory and Dinh, 2005).

Cervical screening participation rates in Australia have been monitored through analysis of Pap Smear Registry data and differ by age, locality and socioeconomic

status (SES) and in cohort studies, by marital status, parity, education level, ethnicity and Indigenous status (CSSB, 2011; Coory et al., 2002; AIHW, 2007; Siahpush and Singh, 2002; Mitchell et al., 1997). The state-wide participation rate for the target age group of women aged 20 to 69 years in Queensland was 57.0% in 2008/09 and is consistently one of the lowest participation rates in Australia (CSSB, 2011). Queensland's participation rates are specifically impacted by a number of factors including the geographical distribution of the population across the state, rapid population increases and workforce issues (including limited availability of female Pap smear providers and poor access to bulk billing services [no out-of-pocket costs], especially in rural and remote areas) (Kirk et al., 1998; CSSU, 2007c. 2005; Kelaher et al., 1997).

1.2 CONTEXT

Advances in scientific knowledge and molecular detection methods have led to significant breakthroughs and technological advancements for the prevention of cervical cancer. Human papillomavirus (HPV) has been universally recognised as the necessary though not sufficient cause of cervical cancer. A prophylactic vaccine against the two most common oncogenic strains of HPV has been developed as a method of primary prevention, as vaccination protects against the inception of the pathologic process caused by HPV that is associated with cervical cancer (Tomatis and Huff, 2001; Frazer et al., 2006; Walboomers et al., 1999). The implementation of the National Human Papillomavirus Vaccination Program (NHPVP) in Australia in April 2007 is anticipated to further reduce its incidence. The primary target age group in NHPVP is girls at school aged 12 years. The two vaccines currently available in Australia provide 90–100% protection against persistent HPV infection and cervical/genital disease due to the two most common anogenital oncogenic HPV types (types 16 and 18), estimated to cause approximately 70-80% of cervical cancers in Australia (NCIRS, 2006b). Due to already existing infections, the effectiveness of these vaccines in reducing cervical cancer incidence will not impact cervical cancer rates for at least one to two decades and is dependent on high rates of vaccine uptake (Brotherton, Kaldor and Garland, 2010; Wright, Van Damme, et al., 2006; Gertig, Brotherton and Saville, 2011).

Successful introduction of a new vaccine program is dependent upon a number of factors including political will, vaccine supply, service delivery capacity, coverage

rates, surveillance of vaccine coverage and safety, and funding (Wright, Van Damme, et al., 2006). One of the key challenges for policy makers and health care providers specific to the HPV vaccine is the need to continue a secondary prevention program, the NCSP, within the context of a primary prevention program. There have been discussions about whether branding the HPV vaccine as a vaccine against cervical cancer, rather than a preventive for a sexually transmitted infection, will influence vaccine acceptability with parents (McClelland and Liamputtong, 2006; Hoover, Carfioli and Moench, 2000). There is also concern that vaccinated women will not participate in screening, which may place them at increased risk for cervical cancer as the vaccine only protects against two oncogenic types of HPV (Brotherton, 2008).

The community needs clear information about HPV and its link with cervical cancer, the link between sexual activity and the acquisition of HPV, the vaccine itself (including the schedule, side effects and efficacy) and the need for cervical screening irrespective of vaccination status (Zimet et al., 2006; Pitts and Clarke, 2002; Waller, McCaffery and Wardle, 2004a). If this is not achieved, the public health impact of the NHPVP may be less than anticipated, especially as low levels of knowledge about the link between HPV and cervical cancer are frequently found in the community (Pitts et al., 2010a; Zimet et al., 2006; Waller, McCaffery and Wardle, 2004a; Pitts and Clarke, 2002; McClelland and Liamputtong, 2006). The majority of these studies have been conducted overseas, although increasingly research has been undertaken in the Australian setting. There are limited studies in Australian of sub-populations whose health status differs from that of the general population, such as women living in rural and remote communities, women from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander women. Recent Australian studies have shown an increase in awareness of HPV and the vaccine as a result of the NHPVP and subsequent media coverage; however knowledge about risk factors and the link between HPV and cervical cancer remain poor (Pitts et al., 2007; Giles and Garland, 2006; Marshall et al., 2007).

In addition to knowledge, women's beliefs and attitudes towards cervical screening and vaccination are important factors influencing their uptake of preventative health behaviours (Pitts et al., 2007; Rosenstock, 1974). There is limited information on these factors from the geographically dispersed population of

Queensland where cervical screening participation rates remain below the national average and are amongst the lowest in the country.

Advances in scientific understanding of the role of HPV in the development of cervical cancer and the availability of prophylactic vaccines have prompted debate about cervical screening policies worldwide, and there are calls for a review of the NCSP in Australia (Wain, 2006; NCSP, 2005; Franco et al., 2006). This review, officially named the *Renewal*, will investigate the role of new technologies such as HPV DNA testing, including the potential for it to replace the Pap smear as the primary screening test used within the NCSP (NCSP, 2012b). In addition, the screening policy will be reviewed as it is out of date with contemporary international recommendations, especially the age of commencement for screening and the screening interval, as women in Australia commence screening at a much younger age and screen more frequently than women in other countries with organised screening programs (National Health Service, 2012; NCSP, 2012b; IARC, 2005). Women need adequate information with which to make informed choices about cervical screening and vaccination, and understand changes related to the NCSP screening policy (Hawkins et al., 2011).

1.3 PURPOSE

This in-depth exploration aimed to describe women's knowledge of cervical cancer and screening and HPV, and their beliefs and attitudes towards Pap smears and the HPV vaccine, to identify women's sources of health information about cervical cancer/screening, HPV and the vaccine and sought their advice on effective methods of disseminating information in their communities. This was the first large study of this topic conducted in the Queensland setting following the implementation of the HPV vaccine.

The outcomes of this study will assist in evaluating previous strategies aimed at reducing the incidence of cervical cancer in Queensland women and inform policy, service delivery and the development of education programs for health providers and women. This aims to ensure the implementation of the NHPVP and any subsequent changes to the NCSP screening policy are based on consumer needs and input.

1.4 SIGNIFICANCE, SCOPE AND DEFINITIONS

1.4.1 Significance

This study investigated for the first time in Queensland, a broad age group of women, between 18 and 70 years of age, explored differences by locality and SES and considered the impact of screening history on women's knowledge about cervical cancer/screening, HPV and HPV vaccination. With the Renewal of the NCSP, this thesis focused on identifying women's perceptions of the current NCSP and the NHPVP. The timeliness of this research will assist in the development of communication strategies to assist women to make informed choices about screening and vaccination and be comfortable with the anticipated changes to the NCSP in the next few years, given the current screening policy has remained unchanged for over 20 years.

1.4.2 Scope

This study was not designed to provide information on specific sub-populations, such as Aboriginal and Torres Strait Islander women, women from culturally and linguistically diverse backgrounds, women with disabilities or lesbian, bisexual, intersex, transgender women. The framework used in this study may be useful for other researchers and can be readily adapted for use with women from diverse populations.

1.4.3 Definitions

The definitions appropriate to this study are described below:

- Area of socio-economic disadvantage - An area could have a low score if there are (among other things), many households with low income, many people with no qualifications, or many people in low skilled occupations whilst an area may have a high score if there are (among other things), few households with low incomes, few people with no qualifications or in low skilled occupations (ABS, 2006b).
- National Cervical Screening Program - the organised approach to cervical cancer screening in Australia, which promotes routine screening with Pap smears every two years for women between the ages of 18 (or two years after first sexual intercourse, whichever is later) and 69 years (NCSP, 2012a).

- National HPV Vaccination Program - the Australian Government funded school-based program routinely delivered to girls in the first year of secondary school (National Immunisation Program, 2012).
- Primary prevention - measures aimed at preventing the start of a pathologic process or the occurrence of a disease (Tomatis and Huff, 2001).
- Secondary prevention - measures for the early detection and prompt intervention on a clinically asymptomatic disease (Tomatis and Huff, 2001).
- Sexual debut - the commencement of sexual activity.
- Underscreened women – women who have Pap smears less frequently than the recommended NCSP interval. For the purposes of this study these women have not had a Pap smear for more than three years.
- Unscreened women – women who have never had a Pap smear.

1.5 THESIS OUTLINE

This thesis is organised as follows. Chapter 2 provides an overview of cervical cancer and describes primary and secondary prevention strategies in Australia, including community knowledge, awareness and acceptability of these strategies. In Chapter 3, the overarching research design of this mixed methods study is described followed by a description of the research design employed for Phase 1 of the study, the methods of the quantitative survey in Chapter 4 and the findings of this survey in Chapter 5. The research design for the qualitative phase of the study, a series of focus groups with women across Queensland, is described in Chapter 6 and the findings of this phase follow in Chapter 7.

In Chapter 8, the research findings from both phases of the study are summarised and discussed within the context of existing research and in the final chapter, Chapter 9, the strengths and limitations of the study are described before discussing the implications of this research for policy makers, health providers and the community and further research into primary and secondary prevention strategies in Australia.

Chapter 2: Primary and Secondary Cervical Cancer Prevention

This chapter begins with the background to cervical cancer incidence and mortality (Section 2.1) and primary and secondary cervical cancer prevention strategies in Australia including the National Cervical Screening Program (NCSP) and the National Human Papillomavirus Vaccination Program (NHPVP) (Section 2.2). The search strategy used to conduct this literature review is outlined in Section 2.3 and in Section 2.4, community knowledge and awareness of cervical cancer prevention strategies, including Pap smears, human papillomavirus (HPV) and HPV vaccination are discussed. The acceptability of cervical cancer prevention strategies, including barriers that impact upon women's uptake of screening and HPV vaccine acceptability by women and parents involved in decision-making processes about vaccination are described in Section 2.5 and the implications from the literature are summarised in Section 2.6.

2.1 BACKGROUND

Worldwide, cervical cancer is the second most common cancer among women. In the year 2000, an estimated 471,000 women were diagnosed with cervical cancer and approximately 233,000 died from this debilitating disease (Ferlay et al., 2001). In developing countries, where almost 80% of cases occur, cervical cancer is the most common cancer among women in many regions (IARC, 2005). Cervical cancer comprised 1.6% cancers in women in 2007 and the mean age of diagnosis was 51.2 years (AIHW, 2011). Squamous cell carcinoma is the most common subtype of cervical cancer worldwide and in Australia was responsible for 63.4% of new cases of cervical cancer reported in 2007 (AIHW, 2011). Other subtypes include adenocarcinoma and adenosquamous carcinoma which comprised almost 25% and less than four percent, respectively, of cervical cancers diagnosed in women that same year (AIHW, 2011).

Risk factors associated with cervical cancer (and HPV) include those that increase the risk of acquiring a sexually transmitted infection, such as multiple sexual partners, early sexual debut, not using condoms, having an uncircumcised sexual

partner and oral contraceptive use. Additional factors include non-participation in cervical screening, high parity and smoking (IARC, 2005; Reid, 2001; Bosch and Muñoz, 2002).

In Australia, the NCSP has been highly successful in reducing the incidence and mortality from squamous cell carcinoma of the cervix due to an organised population-based approach to cervical screening and is one of the great public health stories in this country (Farnsworth and Mitchell, 2003). Incidence rates have decreased from 17.1/100,000 new cases (women aged 20–69 ASR) in 1991 (13.2/100,000 – women - all ages – ASR) to 9.0/100,000 new cases (women aged 20–69 ASR; [6.8/100,000 women of all ages – ASR]) in 2007 (AIHW, 2011).

Cervical cancer has decreased from being the sixth most common cause of cancer death affecting women in 1989 (prior to the introduction of the NCSP) to the 18th most common cause in 2007, which demonstrates the effectiveness of this organised population-based cervical screening program as a secondary prevention strategy (AIHW, 2011). In 2007, 208 women died from cervical cancer (AIHW, 2011). The risk of dying from cervical cancer by 75 years of age was one in 817 and one in 502 women by 85 years of age (AIHW, 2011). Mortality rates amongst women of all ages have decreased from 4.0/100,000 in 1991 to 1.9/100,000 in 2007 (age-standardised rates [ASR]). Mortality was highest in women aged 85 years and older (10.5/100,000). Cervical cancer incidence and mortality rates in Queensland have followed national trends. Incidence and mortality rates in Queensland for the period 2003–2007 were 10.7/100,000 women and 2.2 per 100,000 women respectively.

Cervical cancer incidence and mortality in Australia has been reported to differ by a number of factors including age, geographic location and ethnicity. The incidence of cervical cancer was highest in women aged 35–39 years of age in 2007 and lowest for women aged 20–24 years. Age-specific cancer mortality increases with age and was highest for women in the eligible screening population (20 – 69 years) in women aged 60 to 64 years (AIHW, 2011). In 2003–2007, incidence was higher amongst women from remote locations and very remote areas compared to those in regional areas and major cities at 12.2 new cases per 100,000 women, as were mortality rates with 4.1 per 100,000 women dying from cervical cancer during this period (AIHW, 2011). More recently deaths from cervical cancer have also been

found to be higher amongst women in the lowest socio-economic (SES) group compared to the highest SES group (AIHW, 2011).

Despite the success of the NCSP in Australia, Aboriginal and Torres Strait Islander women are more likely to be diagnosed with, or die from cervical cancer than non-Indigenous women (AIHW, 2011. 2007. 2005b; Homewood, Coory and Dinh, 2005). In jurisdictions where data is of sufficient quality for analysis (Queensland, Northern Territory, Western Australia and South Australia), incidence and mortality rates amongst Aboriginal and Torres Strait Islander women were 20.6 and 10.6 per 100,000 women respectively, in 2003–2007 compared to 8.6 new cases and 1.9 deaths per 100,000 non-Indigenous women, respectively (AIHW, 2011). This demonstrates a disproportionate burden of cervical cancer affecting Aboriginal and Torres Strait Islander women.

There is limited data on cervical cancer incidence and mortality for women in Australia by ethnicity; however higher rates of cervical cancer have been reported in Australia for women from specific countries, such as the former Yugoslavia, Vietnam and Thailand (Taylor et al., 2003; Fernbach, 2002; Jirojwong and Manderson, 2001). The NCSP has, as demonstrated, been highly effective in reducing cervical cancer incidence and mortality in the Australian setting, but specific groups are considered to be at increased risk of disease, primarily due to lower participation in the screening program as described in the next section.

2.2 PRIMARY AND SECONDARY CERVICAL CANCER PREVENTION STRATEGIES IN AUSTRALIA

The detection of pre-cancerous lesions through regular screening of women using the Pap smear has been one of the most widely adopted and effective strategies for preventing cancer related deaths in the world (Anderson, Haas and Shanahan, 2008). The finding that 99.7% of cervical cancer occurs in women who are infected with specific types of high-risk HPV has led to changes in the way the medical and scientific community are approaching the prevention of cervical cancer (Walboomers et al., 1999; Munoz, 2000). Evidence that HPV is a necessary cause of cervical cancer has led to increased technology beyond the Pap smear for the prevention of cervical cancer. This includes prophylactic vaccines against specific types of HPV and the development of molecular methods for detecting HPV that aim to improve

the detection of high grade cervical cancer precursor lesions (Wright, Bosch, et al., 2006).

Primary and secondary prevention programs are available in Australia as population-based strategies to reduce the incidence and mortality of cervical cancer. Primary prevention through the NHPVP was introduced in 2007, whilst secondary prevention through the NCSP, was formally introduced in 1991. These programs are described more fully in the next section.

2.2.1 Cervical Screening

Up to 90% of squamous cell carcinoma can be prevented through regular participation in cervical screening (Hakama, Miller and Day, 1986). The Pap smear, discovered by Dr George Papanicolaou in the early 1940s has led to a dramatic reduction in deaths from cancer of the cervix uteri and is the most common test used to screen for cervical cancer (Barter, 1992). Cervical screening at a population level has been adopted in Australia, North America, Britain and Western European countries (Luke et al., 2007; IARC, 2005). Population-based screening requires significant resources and infrastructure if it is to be effective, which has prohibited its introduction in developing countries (IARC, 2005).

Screening for the prevention of cancer of the cervix using the Papanicolaou smear, has been available in Australia since the 1960s; however it was not until the introduction of an organised approach to cervical screening that significant reductions in cervical cancer incidence and mortality were achieved in this country (AHMAC, 1991; AIHW, 2007). A national cervical screening policy was introduced in 1991 and revised slightly in 1998 (Commonwealth Department of Health and Family Services, 1998). This policy informs cervical screening practice throughout Australia as it specifies the target population to be screened. The current national cervical screening policy in Australia is:

1. Routine screening with Pap smears should be carried out every two years for women who have no symptoms or history suggestive of cervical pathology.
2. All women who have ever been sexually active should start having Pap smears between the ages of 18 and 20 years, or one or two years after first having sexual intercourse, whichever is later.

3. Pap smears may cease at the age of 70 years for women who have had two normal Pap smears within the last five years. Women over 70 years who have never had a Pap smear, or who request a Pap smear, should be screened (NCSP, 2012a).

The NCSP is based on the Australian Population-based Screening Framework which stipulates the screening program will provide more benefit than harm to the people being screened. This framework is based on the World Health Organisation principles of screening developed by Wilson and Junger in which the condition should be an important health problem and have a recognisable latent or early symptomatic stage (Screening Subcommittee, 2008; WHO, 2007a). Other principles included in the framework relate to the benefits and reliability of the test, the importance of a screening pathway and the availability of effective treatment (Screening Subcommittee, 2008). Cervical screening using the Pap smear has been deemed to meet these principles when conducted in the context of an organised screening program (IARC, 2005).

The organised approach to cervical screening has been deemed cost-effective; however the cost-effectiveness and rationale for maintaining a secondary prevention program based on two yearly screening within the context of a primary prevention program has been called into question (Wain, 2006). This has resulted from advanced understanding of the natural history of HPV infection and its role in the development of cervical cancer, the implementation of the NHPVP in Australia and the availability of new technologies, such as HPV DNA testing (Wain, 2006; Canfell, Sitas and Beral, 2006; Bosch et al., 2002).

Regular participation in cervical screening is the primary indicator used to monitor the success of the NCSP. The participation rate is calculated by taking the number of women who had a Pap smear at least once over a two-year period as a percentage of the target population of eligible women aged 20–69 years (CSSU, 2007b). The target population is derived from the 2005–2006 Estimated Resident Female Population obtained from the Bureau of Statistics (ABS), and adjusted for the proportion of women estimated to have undergone a hysterectomy. Each woman is counted once only, despite the number of Pap smears she may have had during the reporting period. Pap smear data is obtained from jurisdictional Pap smear registers, therefore women who choose to opt off i.e. not have their details sent or recorded on

the Register (estimated as 0.5 to 1.5% of eligible women) are not able to be counted and are excluded from this rate (CSSB, 2011).

In Australia in 2008/09, more than 58% of women participated in two yearly cervical screening as recommended by the NCSP (AIHW, 2011). Women who are unscreened (women with no history of a previous Pap smear) or underscreened (women whose screening history was less than the recommended screening interval) are more likely to be diagnosed with cervical cancer. In 2008, of the 65 Queensland women aged 30–69 years diagnosed with squamous cell carcinoma on histology, 53 (81.5%) did not have a Pap smear recorded on the Pap Smear Register (PSR) in the four years prior to their diagnosis and 41 (63.1%) had not had a routine Pap smear recorded for more than 10 years (CSSB, 2011).

The state-wide participation rate for the target age group of women aged 20 to 69 years in Queensland was 57% in 2008/09 and is consistently one of the lowest participation rates in Australia (AIHW, 2011). A number of strategies have been specifically aimed at increasing the participation of women in Queensland, such as a social marketing campaign conducted between 2006 and 2009, the Mobile Women's Health Service, the Healthy Women's Initiative and workforce strategies, for example, the GP Cervical Screening Update Program (CSSU, 2007c). The Mobile Women's Health Service is a network of 15 registered nurses and two Aboriginal and Torres Strait Islander health workers who travel to rural and remote areas to provide cervical screening and other women's health services, whilst the Healthy Women's Initiative is a network of Aboriginal and Torres Strait Islander health workers whose role is to promote cervical screening in their communities and support women to access services, including follow up and treatment. These two strategies were implemented in Queensland to help address access issues facing the widely dispersed population in Queensland and assist women to access to female providers (CSSU, 2007c).

Cervical screening participation rates in Australia have been shown to differ by age, locality, socioeconomic status (SES), marital status, parity, education level, ethnicity and Indigenous status (Coory et al., 2002; AIHW, 2007; Siahpush and Singh, 2002; Mitchell et al., 1997; CSSU, 2007b). PSR data reveal that unscreened and underscreened women in Queensland reflect those identified nationally. Queensland women under 30 and over 60 years of age are less likely to have two

yearly Pap smears, as are women who live in areas of high socio-economic disadvantage, remote or large outer metropolitan areas (other metropolitan areas – Australian Standard Geographical Classification (CSSU, 2007b). Queensland's participation rates are thought to be affected by a number of factors including the geographical distribution of the state, rapid population increases and workforce issues, including the availability of female providers and bulk billing services, especially in rural and remote areas (CSSU, 2007c).

Demographic factors identified in cohort studies that impact on women's participation in cervical screening or incidence of cervical abnormalities/cancer include socioeconomic status, rurality and education level (Luke et al., 2007; Dietsch, Gibb and Francis, 2003; Siahpush and Singh, 2002). Marital status was the strongest predictor of awareness, receipt and recency of Pap smear amongst women who participated in the 1995 National Health Survey (Siahpush and Singh, 2002). There is also evidence in both Australian and international studies, that women who smoke are less likely to have regular Pap smears (Pearlman et al., 1999; Smith et al., 2011; Coughlin et al., 2004).

There is limited recent data available on cervical screening participation rates for women by Indigenous status and ethnicity as Pap smear registers do not receive information about women's cultural background. In Queensland, cervical screening participation rates of Aboriginal and Torres Strait Islander women have been estimated by discrete communities (where the proportion of Aboriginal and Torres Strait Islander Australians is estimated to be greater than 90% of the resident population) or through self-reported cohort studies (Coory et al., 2002; Binns and Condon, 2006). The overall cervical screening participation rate in discrete Aboriginal and Torres Strait Islander communities in Queensland in 1999–2000 was 41.1% (95% C.I. 40.2%–42.7%), which was 30% lower than the state average rate of 59.1% (Coory et al., 2002). These findings are similar to Aboriginal and Torres Strait Islander women's cervical screening participation rates in the Northern Territory where participation for the same reporting period was 44% (95% C.I. 42.7%–45.4%) and lower than national average participation rates (Binns and Condon, 2006; Coory et al., 2002; Bowden F et al., 1998).

There have been multiple reasons identified as to why Queensland Aboriginal and Torres Strait Islander women are less likely to participate in regular Pap smears.

These include low levels of knowledge and awareness of cervical cancer, cervical screening and the concept of prevention, confusion about Pap smears and tests for detecting sexually transmitted infections (STIs), associating the need for Pap smears with current sexual activity commonly expressed as "No sex, no Pap" and only having Pap smears when pregnant. Other reasons include fear about lack of confidentiality, cancer or having an abnormality detected, lack of access and/or choice of service providers particularly in remote areas and a lack of culturally effective and culturally safe resources and services (Kirk et al., 1998).

Lower cervical screening participation rates have also been reported for women from culturally and linguistically diverse (CALD) backgrounds in Australia (Jirojwong and Manderson, 2001; Fernbach, 2002; Taylor et al., 2003; Kelaher et al., 1997). The factors for low participation are similar to those documented for Aboriginal and Torres Strait Islander women and also include lack of awareness of cervical screening practices in Australia, specific cultural and spiritual beliefs about health and illness and the belief cancer is incurable (Kelaher et al., 1997). Poor knowledge of screening was identified in the National Women's Health Survey (2005) as the most significant risk for lack of cervical screening for women born in the Middle East and Asia (Siahpush and Singh, 2002).

Secondary prevention through cervical screening has been a long standing program in the Australian setting; however advances in scientific understandings about the role of HPV has revolutionised cervical cancer prevention strategies as described in the next section.

2.2.2 HPV Vaccination

The causal role of HPV in cervical cancer has been firmly established and it is widely accepted that infection with HPV is necessary, but not sufficient for the development of cervical cancer, due to overwhelming evidence that over 99.7% of cervical cancers test positive for HPV (Walboomers et al., 1999; Munoz et al., 2006). There are more than 100 types of HPV that have been characterised molecularly, of which 40 are known to preferentially infect the squamous epithelium of the genital tract (Wright, Bosch, et al., 2006). High risk genital HPV genotypes are those that have been linked with the development of cervical cancer and comprise 15 of the genotypes that infect the human anogenital tract (Baseman and Koutsky, 2005).

Genital HPV is the most common sexually transmitted infection worldwide. Over 50% of sexually active women in most populations (and probably men) are thought to be infected with HPV at some point in their lives (Wright, Bosch, et al., 2006). HPV infection is most common in the first few years of sexual activity and is frequently detected by the Pap smear as an acute lesion on the cervix, commonly reported as a low grade squamous intraepithelial lesion, although it may also manifest as a high grade lesion (Stoler, 2000). The natural history of HPV infection is not completely understood, although it is known that HPV is not sufficient for the development of cervical cancer. The average duration of infection with HPV is eight to 14 months and the majority of lesions (98%) resolve spontaneously without treatment (Baseman and Koutsky, 2005; Munoz et al., 2006).

Some women, however, have persistent infection with high risk HPV. For some this does not lead to any adverse consequences but for a small number of women (less than 1%), this persistent infection can progress to cervical cancer over a period of 10–20 years (Munoz et al., 2006). The biological characteristics of persistence are not well characterised, but some factors are thought to increase the risk of progression from persistent HPV infection to cervical cancer (Wright, Bosch, et al., 2006). These include immunosuppression (e.g. women taking immune suppressant therapy and HIV positive women), higher parity, long term oral contraceptive use, age (greater than 30 years), the size and severity of the precursor lesion and smoking (Bosch and de SanjosÃ, 2003).

Worldwide prevalence (for all major world regions) of cervical HPV DNA in women with normal cytology has been estimated at any point in time at 10%, with highest prevalence (17%) amongst women under 34 years of age (de Sanjose et al., 2007). In a meta-analysis of 78 published studies, a second peak in HPV prevalence in women over 45 years was observed in all regions excluding Asia. No data were available for Australia or New Zealand for inclusion in this meta-analysis. The overall prevalence of HPV infection in women with normal cytology was estimated to be 15.5% in less developed world regions and 10% in more developed regions (de Sanjose et al., 2007).

The majority of studies used in large meta-analyses to determine HPV prevalence worldwide have been conducted in Europe, Asia, North America and South/Central America and Africa. A large study, the Women Human

Papillomavirus Indigenous Non-Indigenous Urban Rural Study (WHINURS), was undertaken to determine HPV genotype prevalence in Australia. This study found the prevalence of types 16 and 18 HPV infection in the Australian female population did not differ by Indigenous status or age, but differences were found in the prevalence of risk factors, such as smoking and Pap smear abnormalities (Garland et al., 2011a). A meta-analysis of seven Australian studies containing 553 cervical cancers found over 80% of cervical cancers contained types 16 and 18 and that 77.7% of cervical cancers (excluding those containing both types), could have been prevented through vaccination (Brotherton, 2008).

The development of prophylactic vaccines against HPV has been one of the most significant breakthroughs in the prevention of cervical cancer. In developing countries, the primary aim of HPV vaccination is to prevent cervical cancer. In most developed countries with organised screening programs (and corresponding low cervical cancer incidence), the most important goal of HPV vaccination programs will be to reduce the number of women with abnormal cytology results, particularly high-grade abnormalities, which cause a significant burden to women and the health care system (Wright, Bosch, et al., 2006; Kyrgiou et al., 2006).

There are currently two vaccines approved for use in Australia, Gardasil® and Cervarix®. The former, a quadrivalent vaccine, protects against HPV types 6, 11, 16 and 18 (types 6 and 11 are responsible for 90% of genital wart infections) whilst the latter is a bivalent vaccine that protects against HPV 16 and 18 only (NCIRS, 2006b; Wright, Bosch, et al., 2006). The findings of phase 2 and 3 clinical trials of healthy young women who were naïve for the HPV types included in the vaccines, found both vaccines to be highly immunogenic with seroconversion rates to all targeted types of HPV of over 98% and durability of protection of 36 months for the quadrivalent vaccine and 53 months for the bivalent vaccine (Koutsky and Harper, 2006; Garland, 2007b). In addition, both appear to be generally safe and well tolerated with injection site and minor systemic events the most commonly reported adverse events (Koutsky and Harper, 2006). The vaccine is administered by a series of three injections given within a six month period and has been shown to be highly effective at preventing infection with HPV types 16 and 18 and therefore is estimated to prevent up to 70% of cervical cancers (Garland, 2007b). The vaccine is most effective if given to females prior to the commencement of sexual activity and

has also been found to be more immunogenic if administered to adolescent girls (Frazer et al., 2006; NCIRS, 2006b).

In Australia, Gardasil® was initially approved for use for females aged nine to 26 years and males nine to 12 years by the Therapeutic Goods Administration (TGA), and has been on the market since August 2006. More recently it has been approved for use in females aged nine to 45 years and males nine to 26 years (National Immunisation Program, 2012). Cervarix® was approved by the TGA in June 2007 for women aged 10–45 years. The Australian Health Minister made a public announcement in November 2006 that Australia would become the first nation in the world to introduce a publicly funded primary prevention program against cervical cancer by implementing the NHPVP from April 2007. The NHPVP is a school-based program targeting girls aged 12–13 years. A catch-up program for girls attending school was introduced in 2007 until 2009 where older girls attending school (until the final year) were offered vaccination. In addition a catch-up program for young women up to the age of 26 years (available from July 2007 until 2009) was introduced through general practice or alternative health services that traditionally offer vaccination programs (e.g. Aboriginal Medical Centres, Community Health Centres etc). In November 2011, the Pharmaceutical Benefits Advisory Council Public announced a recommendation to extend the NHPVP to include males, 12 to 13 years of age, and a two year catch-up program; and on 12 July 2012, it was publicly announced boys would be included in the NHPVP (Australian Government, 2012).

Reported HPV vaccination coverage rates in Australia are encouraging with coverage rates equivalent to other vaccines in adolescents. As at March 2011, three-dose coverage was approximately 70% in the school-based program with lower rates observed in the catch-up program (Gertig, Brotherton and Saville, 2011). HPV vaccination coverage is monitored through the National HPV Vaccination Register, which receives data from all jurisdictions and will be invaluable in evaluating the impact of the vaccine on HPV related cervical disease if linkage with Pap smear registers occurs in the future.

With increased knowledge about the natural history of HPV, advances in screening technologies have also occurred and are described next.

2.2.3 New Technologies

The Pap smear has remained the most effective cervical screening test for use in population screening programs in high and medium resourced countries despite its poor sensitivity (International Agency for Research on Cancer, 2005). Attempts to increase the sensitivity and automate cervical screening have led to the development of a number of new technologies. These include liquid-based cytology, such as ThinPrep® and SurePath® and automated screening devices, for example the Thin-Prep Imager® and FocalPoint®. Liquid-based cytology is not publicly funded in Australia at present as a review conducted by the Medical Screening Advisory Committee in 1998 determined there would be limited benefit and substantial cost involved in publicly funding these technologies given the effectiveness of the NCSP (AHTAC, 1998).

Testing methods to determine the presence of HPV or persistent HPV infection have been the focal point of research into new testing methods since the confirmation of this virus as the necessary cause of cervical cancer. The role of HPV DNA testing has been explored as it has many applications within the context of organised screening. HPV DNA testing has been considered as a primary screening tool to replace cytology, as a triage test for women following an equivocal Pap smear result, and as a 'test-of-cure' following treatment for a high-grade abnormality (Garland, 2007a). HPV DNA testing in Australia has only been endorsed to date as a 'test of cure' (National Cervical Screening Program, 2005; Garland, 2007a).

HPV DNA testing is reported as highly sensitive for primary screening and the detection of underlying high-grade disease (Arbyn et al., 2006). One of the drawbacks of primary screening with HPV DNA testing however, is the test's low specificity in excluding the absence of high-grade cervical intraepithelial lesions when compared to cytology screening, especially in women under the age of 30 years (Goldie, Kim and Wright, 2004; Arbyn et al., 2006). HPV screening in young women has been reported as inefficient as HPV infections and associated mild lesions almost always spontaneously regress and therefore a positive result will potentially lead to unnecessary investigations (Arbyn et al., 2006).

With the advent of the HPV vaccine; however, the role of HPV DNA testing as a primary screening tool is gaining increased attention (Cuzick et al., 2000; Franco et al., 2006). The low sensitivity of the Pap smear and subsequent high false-positive

rate has been described as its most critical limitation (Franco et al., 2006). The sensitivity of the Pap smear is increased through repeated testing and requires significant resources for the establishment of systems to ensure coverage, quality and compliance (International Agency for Research on Cancer, 2005). The use of the most highly sensitive test (HPV DNA testing) for primary screening and a highly specific test (the Pap smear) for triaging cases has been suggested in recent cervical screening algorithms currently under consideration and has recently been endorsed as the screening pathway in the Netherlands (Meijer, 2011; Wright, Bosch, et al., 2006; Franco et al., 2006).

Self testing for HPV DNA has also been explored as an alternative testing method for women in low resource countries and for increasing the participation of non-responders in countries with organised screening programs (Anhang et al., 2005; De Alba et al., 2008; Igidbashian et al., 2011; Waller et al., 2006). HPV DNA is found in the cells shed from the surface epithelium of the cervix and vagina, therefore testing of these exfoliated cells is an alternative method of screening (Morris and Rose, 2007). The findings from studies investigating the diagnostic accuracy of self collected HPV specimens have been positive (Quincy, Turbow and Dabinett, 2012). The sensitivity and specificity of self-collected HPV samples when compared to physician collected samples has been found to be as sensitive in detecting high risk HPV DNA in a meta-analysis of 18 studies (Petignat et al., 2007). The sensitivity and specificity of self collected tests when compared with physician samples as the gold standard for detecting high risk HPV and cervical abnormalities found the self collected specimen had a sensitivity of 92.6% and specificity of 87.1% for detecting high risk HPV. A higher sensitivity for detecting cervical abnormalities than physician collected samples was also evident, although the latter was not significant (De Alba et al., 2008). These studies indicate the role of self collection for HPV DNA requires consideration in future screening programs.

The Renewal

Advances in understanding the role of HPV in the development of cervical cancer and the availability of prophylactic vaccines have prompted debate about cervical screening policies worldwide and there are calls for a review of the NCSP in Australia (Wain, 2006; NCSP, 2005; Franco et al., 2006). With these advances there is increasing marketing of technologies by commercial interests, including liquid-

based cytology; adjunctive HPV DNA testing and self collected testing for HPV DNA and cytology in the lay press and via the Internet. These are promoted as essential methods for protecting women against cervical cancer, despite a reported lack of evidence they are of any benefit within the context of the NCSP (AHTAC, 1998). As a result women are faced with confusing messages from both health providers and the media about HPV, cervical cancer and effective prevention methods.

Women's knowledge and understanding of HPV and cervical cancer will be critical to avoid unnecessary psychological distress if HPV testing is introduced as a screening tool and to ensure they have adequate information on which to make informed choices about cervical screening and vaccination (McCaffery et al., 2006; Giles and Garland, 2006; Marlow, Waller and Wardle, 2007). In addition, this knowledge is essential to assist women to understand policy changes related to the NCSP and the subsequent management of women with screen-detected abnormalities (Hawkins et al., 2011).

The consideration of these issues is under consideration with the Renewal of the NCSP which commenced in 2011. The objectives of the Renewal are to:

- assess the evidence for screening tests and pathways, the screening interval, age range and commencement for both vaccinated and non-vaccinated women;
- determine a cost-effective screening pathway and program model;
- investigate options for improved national data collection systems and registry functions to enable policy, planning, service delivery and quality management; and
- assess the feasibility and acceptability of the renewed NCSP for women (NCSP, 2012b).

The Renewal aims to ensure that all Australian women have access to an evidence-based program that continues to improve health outcomes of Australian women. It is therefore imperative that the renewed NCSP reaches a higher proportion of women at risk for cervical cancer and participation in cervical cancer prevention strategies, such as cervical screening and vaccination are improved.

A key challenge, therefore, is to encourage eligible women who are unscreened and underscreened for cervical cancer to participate regularly and achieve high population rates of vaccination in younger cohorts. Understanding why women do not participate in cervical cancer prevention strategies in the Australian setting is crucial to achieve higher participation rates and coverage (Garland, Skinner and Brotherton, 2011b).

Factors such as age, locality, socioeconomic disadvantage, and Indigenous status are linked with decreased cervical screening participation along with a number of knowledge deficits and barriers. Knowledge about cervical cancer and screening and barriers to screening participation are described in the next section.

2.3 SEARCH STRATEGY

A review of the literature was undertaken to inform the design of this study and provide insight into existing research about women's knowledge of HPV and cervical cancer and knowledge and attitudes about cervical screening and the HPV vaccine. Searches of medical, nursing and allied health databases including Academic Search Elite, Medline and CINHAL were undertaken using the key words, cervical cancer, cervical screening, Pap smears/tests, human papillomavirus (HPV), HPV vaccination, awareness, acceptability and other terms generated by these searches. In addition, citations included in publications resulting from these searches were sourced and also led to the identification of other citations relevant to this inquiry.

2.4 COMMUNITY KNOWLEDGE AND AWARENESS

Knowledge is recognised as a significant predictor of action in all social cognition models of behaviour, although knowledge alone does not lead to behaviour change (Pitts and Phillips, 1998). Whilst health behaviour theories are underpinned by the understanding that individuals' perceptions, motivation and skills and the social environment in which they live influences their behaviour, it is also recognised that cognitions, namely what people know and think, affects how they act and that knowledge is necessary, although not sufficient, to produce most behaviour change (Rimer and Glanz, 2005).

Knowledge about cervical cancer/screening has been explored as an important factor that influences women's participation in cervical screening over the past three decades with the inclusion of knowledge of HPV and HPV vaccination in more recent studies. Whilst many studies explore all these factors simultaneously, they are described in the following sections separately.

2.4.1 Cervical Cancer/Screening Knowledge

Australian women have been found to have high levels of uncertainty about the cause and risks associated with cervical cancer, good knowledge about the recommended frequency of screening and poor knowledge about when to commence and cease screening (Giles and Garland, 2006; Shand, Burney and Fletcher, 2010; Jirojwong and Manderson, 2001; Wollin and Elder, 2003). In a cross-sectional computer assisted telephone interview (CATI) survey conducted in South Australia prior to the introduction of the HPV vaccine, 79% of male and female respondents were uncertain about what caused cervical cancer with only seven percent identifying the cause was viral (Marshall et al., 2007).

Quantitative and qualitative studies conducted in other countries with young women and women of all ages also reveal high levels of uncertainty and limited awareness of the causes and risk factors associated with cervical cancer (Smith, French and Barry, 2003; Pitts and Clarke, 2002; Waller, McCaffery and Wardle, 2004a; Waller et al., 2005; Marlow, Waller and Wardle, 2007; Mays et al., 2000; Pearlman et al., 1999). In most studies, women identify that sexual activity is a risk factor; however, there is limited understanding of how sex is linked with cervical cancer and whether this is trauma-related or related to the acquisition of a sexually transmitted disease (Waller et al., 2005; Agius et al., 2010b; Marshall et al., 2007; Waller, McCaffery and Wardle, 2004a).

This uncertainty about the link between sexual activity and cervical cancer has been attributed to suppression of this information in public messages and policy, to avoid increasing stigma and anxiety amongst women about participating in cervical screening, as they may perceive others to consider them as promiscuous if they were to receive a positive result (Braun and Gavey, 1999. 1999b; Waller et al., 2005). However, failure to make this explicit has also led to uncertainty, whereby women may either not perceive themselves at risk, as they are not 'promiscuous', despite having had more than one sexual partner in their lifetime or are not empowered

through appropriate information to engage in activities to reduce their risk of acquiring HPV (Braun and Gavey, 1999b).

The importance of ensuring women have accurate knowledge of the sex-related risks associated with cervical cancer was also found in a British study as women who knew of the link between cervical cancer and HPV as a sexually transmitted infection were more readily able to integrate new information about HPV into their existing causal framework than less knowledgeable participants (Waller et al., 2005). Armstrong and Murphy (2008), in their study also concluded that when women don't know about HPV and its link with sexual activity and cervical cancer they weave their own meanings from health messages that are not explicit or contain incomplete or fragmented information, which often leads to misconceptions.

In other studies, women also had limited knowledge of the purpose of Pap smears or the meaning of an abnormal result, with the Pap smear often associated with the prevention of other cancers or gynecological conditions (Mays et al., 2000; Moreira et al., 2006; Eaker, Adami and Sparen, 2001). Differences in knowledge were observed by marital status, parity, education, race, income and screening status, although not all studies included representative samples or employed methods to adjust for confounding (Eaker, Adami and Sparen, 2001; Moreira et al., 2006; Pearlman et al., 1999; Hawkins et al., 2011). Age, educational status and screening status were factors associated with differences in cervical cancer/screening knowledge when representative sampling and regression models were employed (Eaker, Adami and Sparen, 2001; Pearlman et al., 1999; Waller, McCaffery and Wardle, 2004a).

2.4.2 HPV Awareness and Knowledge

The majority of studies exploring HPV awareness and knowledge have focused predominantly on women and even when studies included both males and females, women were frequently over-represented (Waller, McCaffery and Wardle, 2004a; Baer, Allen and Braun, 2000; Mays, Sturm and Zimet, 2004). Both qualitative and quantitative methods have been used by researchers in their investigations abut HPV knowledge, with some studies using a combination of methodologies.

Awareness of HPV and its link with cervical cancer has increased in Australia following the introduction of the NHPVP. Prior to its introduction, HPV awareness

and knowledge was poor in the few studies conducted, with the exception of one study in which 89% of participants aged 18 to 30 years of age had heard of HPV (Giles and Garland, 2006; Pitts et al., 2007; McClelland and Liamputtong, 2006). However, as the authors acknowledged this high awareness was attributed to selection bias as it included women participating in a vaccination trial and attendees at a dysplasia clinic (Giles and Garland, 2006). Awareness amongst a university sample of women conducted in the first phase of the NHPVP was found to be much lower, with only 45% of young women whose average age was 19 years having heard of HPV (Juraskova et al., 2011).

Public knowledge has been compared and substantial increases in awareness of HPV identified in the Australian context; from 12% in 2006 to 51% in 2007 and 63% in 2008 (Pitts et al., 2010a). The majority of men and women aged 18–70 years participating in the fourth wave of the Australian Longitudinal Study of Health and Relationships Study (66%) were aware HPV was associated with cervical cancer, 50% knew it was associated with abnormal Pap smears and 44.5% were aware of its association with genital warts. Significant predictors of knowledge were associated with age, higher education and older age of sexual debut. There was still, however, considerable uncertainty about the link between HPV and cervical cancer amongst women with 25% of women responding 'don't know' (Pitts et al., 2010a). Increased awareness of HPV and its link with cervical cancer is expected given mass media campaigns and information dissemination regarding the HPV vaccine. Of note; however is that increased awareness of the link between HPV and abnormal Pap smears and genital warts was not found in this study, which was conducted after the implementation of the NHPVP (Pitts et al., 2010a).

Awareness and knowledge amongst Australian year 10 and 12 high school students in 2008 was not as high as their older counterparts, with only 33% having heard of HPV and only 25% knowing of the association with cervical cancer (Agius et al., 2010b). Increased awareness of HPV was also found in an on-line questionnaire of 18–26 year olds in which 94% had heard of HPV, although this was a small non-representative sample. Whilst most participants had heard of HPV, their responses indicated misconceptions, for example, 72% believed that HPV causes infertility (Shand, Burney and Fletcher, 2010). This was also found in a qualitative study conducted with girls and parents in NSW who had low levels of knowledge

about HPV, how it is transmitted and the association with cervical cancer, despite receiving information through the school-based vaccination program and making decisions about whether to participate in HPV vaccination (Cooper Robbins et al., 2010a).

Women reported the majority of the information they received on HPV was through the media which is expected given the extensive media coverage resulting from its introduction and the awarding of 'Australian of the Year' to one of the vaccines' creators and leading researchers, Professor Ian Frazer (Juraskova et al., 2011; Pitts et al., 2007). Significant information gaps in newspaper articles published between October 2006 and December 2009, have been identified particularly in relation to the absence of an association between sexual activity and HPV and highlight the importance of ensuring additional sources of information are available to supplement the information the community is exposed to through mass media (Cooper Robbins, Pang and Leask, 2011; Kelly et al., 2009).

Knowledge and awareness studies conducted overseas also indicate low levels of awareness of HPV and its link with cervical cancer. Many studies were conducted with women and often involved university samples or women attending health clinics, including obstetric/gynaecology and sexual health clinics (Mays et al., 2000; Waller et al., 2003; Pitts and Clarke, 2002; Donders et al., 2009). Awareness of the link between HPV and sex ranged from 11% to 33% across studies and was found to differ significantly by age, education and income in an omnibus survey conducted in the United Kingdom (Marlow, Waller and Wardle, 2007).

Studies exploring in-depth knowledge of HPV, including focus groups and in-depth interviews found knowledge deficits amongst participants about the transmission of HPV, symptoms, prevention and the link with cervical cancer (Vanslyke et al., 2008; Baer, Allen and Braun, 2000; Hoover, Carfioli and Moench, 2000; Moreira et al., 2006). Awareness increased with the introduction of the HPV vaccine as observed in Australia, but remained poor when no public awareness activities had been undertaken (Wong, 2011; Donders et al., 2009; Marlow, Waller and Wardle, 2007).

Awareness and knowledge of HPV has implications on social acceptance of the HPV vaccine as research indicates vaccines against sexually transmitted infections are more acceptable if the disease they aim to prevent is viewed as an important

health issue with serious consequences (Zimet, 2005a). This is particularly pertinent as one of the main factors associated with acceptance of HPV immunisation among mothers of teenage girls is perception of risk (Lazcano-Ponce et al., 2001). Mays et al, (2004), argue that for less familiar infections such as HPV, comprehensive educational campaigns about the specific protective benefits of vaccines for sexually transmitted infections may be needed to enhance parental acceptance, especially as it is parents who play a key role in consenting to their children's participation in HPV vaccination (Pitts et al., 2007; Zimet, 2005a).

In the next section, the acceptability of cancer prevention strategies is explored with a focus on Pap smears which have been the primary screening test used in the Australian context, HPV testing which is under review for inclusion in future screening pathways and HPV vaccination.

2.5 ACCEPTABILITY OF CERVICAL CANCER PREVENTION STRATEGIES

2.5.1 Pap Smears

The acceptability of the test used in a screening program is considered an important component of any population-based screening program (Screening Subcommittee, 2008). Approximately 60% of Australian women participate regularly in cervical screening; however women who screen regularly and those who do not, describe a number of barriers that impact upon the acceptability of the Pap smear as a screening test.

Barriers impacting upon women's participation in cervical screening have been explored with women in all countries and are well documented. The majority of studies have been conducted using convenience and non-random sampling methods. However, despite their limitations, many of these studies provide insight and often in-depth information about women's perceptions and acceptance of cervical screening. Lauver identified three types of barriers to cervical screening participation (Lauver, 1992). These were practitioner, system and client related barriers. Practitioner related barriers include concerns about client embarrassment, familiarity with the woman, lack of time and lack of discussion about screening between practitioner and client. The majority of cervical screening in Australia occurs in the general practice setting and general practitioners (GPs) are well placed

to provide opportunistic and systematic cervical screening for clients due to their large female client base (CSSU, 2007c; Fiebig et al., 2009). However, despite this, less than 30% of women in a CATI survey conducted in Queensland in 2005, reported they were prompted by general practice staff (GP, Practice Manager/Nurse or receptionist) to have their most recent Pap smear (CSSU, 2005).

A study conducted in New South Wales found differences in GPs' recommendations who were more likely to recommend screening to women of higher socioeconomic status and women who were not their regular patients (Fiebig et al., 2009). Some medical practitioners are also not comfortable providing cervical screening, especially as this has not been a formal part of medical education in Australia (Robertson et al., 2003).

System related barriers include barriers, such as accessibility of services in relation to location (the service is hard to get to), timing (many women work or care for children during office hours when most services are offered) and cost to the client of screening tests (Kwok, White and Roydhouse, 2011; Stewart and Thistlethwaite, 2010; Smith, French and Barry, 2003). Access is particularly important for women in rural and remote areas of Queensland who frequently have reduced access to a choice of provider and affordable services due to limited bulk billing services in these locations (CSSU, 2007c). The costs associated with cervical screening have become increasingly important in the Australian setting and are reflected in lower participation rates by women from areas of high socio-economic disadvantage (Robertson, 2006; AIHW, 2011). Unlike breast cancer and bowel cancer screening, the only other two population-based screening programs in Australia, women more often than not have to pay to participate in the NCSP. This includes the cost of the consultation (above the Medicare rebate) unless the woman attends a bulk billing practice, laboratory fees if the test is not bulk billed and increasingly, the cost of adjunctive tests, such as liquid-based cytology and HPV DNA testing, if these are recommended by the practitioner.

Client related barriers are associated with beliefs, norms and affect regarding screening (Lauver, 1992). The most consistent client related barriers across studies are embarrassment and discomfort in both Australian and international studies (Jirojwong and Manderson, 2001; Van Til, MacQuarrie and Herbert, 2003; Blomberg et al., 2008; Fernbach, 2002; Vanslyke et al., 2008; Smith, French and Barry, 2003;

Orbell, 1996). In focus groups conducted in the USA, women described this as the 'yucky factor' (Smith, French and Barry, 2003).

Studies have indicated that women prefer a female practitioner to provide cervical screening and lack of access to a female provider presents as a barrier. (Fiebig et al., 2009; Christie, Gamble and Creedy, 2005; Majeed et al., 1995; Van Til, MacQuarrie and Herbert, 2003; CSSU, 2005). This is particularly relevant for Aboriginal and Torres Strait Islander women and women from CALD backgrounds (Kelaher et al., 1997; Kirk et al., 1998). Other client related factors include lack of time, low knowledge of screening, low appreciation of the benefits of screening and perception of risk. Uncertainty of the reliability of Pap smears and what an abnormal result means has been identified in overseas studies as factors that influence both older and younger women's perception of the benefits of screening (Blomberg et al., 2008; Kahn et al., 2007; Eaker, Adami and Sparen, 2001; Smith, French and Barry, 2003). Other factors that have been identified as client-related barriers include fear of the unknown, obtaining results or the procedure itself, lack of familiarity with the provider and previous negative experiences (Jirojwong and Manderson, 2001; Kirk et al., 1998; Fiebig et al., 2009; Kelaher et al., 1997; Blomberg et al., 2008; Vanslyke et al., 2008; Oscarsson, Wijma and Benzein, 2008).

These barriers indicate some disparity between provider and client related barriers. Women are more likely to have a Pap smear if their practitioner recommends it; however practitioners' recommendations in some studies indicate this is not ideal or that this occurs differently for some women based on their limited familiarity with the provider or their socioeconomic status (Fiebig et al., 2009). Women on the other hand prefer to attend a provider they know and trust. Enablers to assist women to overcome the barriers to screening include access to a female practitioner, the use of reminder systems to help prompt them to attend, access to free screening, public education and providers who have good communication skills and technique (Smith, French and Barry, 2003; Donders et al., 2009; Pearlman et al., 1999; Wendt, Fridlund and Lidell, 2004).

These factors suggest cervical screening has the potential to have negative consequences for some women and the need to ensure women are provided with pre-test information and give informed consent is considered ethically imperative to

avoid harm (Posner et al., 2006; Barratt et al., 2002; Alder and Foxwell, 1999; Anderson and Nottingham, 1999; Chew-Graham et al., 2006).

Exploration of the barriers impacting on women's participation in cervical screening remains an important topic of research especially if more complex screening pathways for cervical cancer are to be introduced into the Australian setting. These pathways include HPV DNA testing and women's acceptance of this test also warrants attention and is discussed in the next section.

2.5.2 HPV Testing

Increasing evidence to support HPV DNA testing as a primary screening or reflex test for cervical cancer and support for its inclusion in screening pathways has prompted researchers to investigate women's acceptance of this new technology. Of particular interest are the issues that are raised with the incorporation of a test for a sexually transmitted infection into a cancer screening program (McCaffery et al., 2006; Waller, McCaffery and Wardle, 2004a). Prior to the discovery of HPV there was limited association in public health messages between sexual health and cervical screening and even with the advent of the HPV vaccine, its promotion as the 'cervical cancer vaccine' in the Australian setting has supported this avoidance of being explicit about the vaccine preventing a sexually transmitted viral infection (Waller, McCaffery and Wardle, 2004a; Cooper Robbins, Pang and Leask, 2011). With low levels of HPV knowledge and its link with cervical cancer evident in all studies, irrespective of their representativeness as discussed earlier, there is concern that focusing on the role of a sexually transmitted infection as a cause of cervical cancer may lead to increased stigma, shame and distress for women and that women who receive a positive test may be labelled as promiscuous (McCaffery et al., 2006; Waller, McCaffery and Wardle, 2004a; Marshall et al., 2007).

The psychological impact of HPV testing as a primary screening test has been investigated as a potential barrier for women. Receiving a positive HPV DNA test was found to cause women to feel stigmatised, anxious, stressed and worried in a qualitative study of women involved in clinical trials of HPV DNA testing in the United Kingdom (McCaffery et al., 2006). This finding was also found in a similar study conducted with women from different ethnic backgrounds who were shocked, worried, surprised and fearful when they were given information that cervical cancer was linked to a sexually transmitted infection (McCaffery et al., 2003). The

possibility of receiving a positive HPV DNA test raised concern for these women, especially Indian and Pakistani women, that the test may be used as a test of fidelity or faithfulness and may potentially lead to unwanted messages being conveyed to partners, their families or the community (McCaffery et al., 2003). Higher levels of anxiety, concern and distress were also found in women who received a positive HPV test conducted as a reflex test after a low grade Pap smear result (Maissi et al., 2004). There were three independent predictors of anxiety in this study; age (younger women had higher anxiety), perceived risk and uncertainty about the meaning of the result. Perceived risk and uncertainty were associated with increased concern and distress. These consequences were of higher magnitude in HPV positive women than those with normal Pap smear results and those with the same Pap smear result who were not tested or tested negative to HPV, although anxiety and distress in these women were found to be short term consequences in a follow-up study six months later (Maissi et al., 2004; Maissi et al., 2005).

Younger women also expressed anticipated feelings of shame, stigma and guilt if they were diagnosed with HPV in a qualitative study of American adolescent and young women attending a teen health centre (Kahn et al., 2007). Their cognitive understanding about HPV testing and Pap smears was found to profoundly influence how these young women created personal meaning from these results (Kahn et al., 2007). In a small study also conducted in USA in which 20 women aged 23–80 years participated in in-depth interviews, women when faced with the choice between reflex testing for HPV after a potential abnormal Pap smear or a follow-up Pap smear in six months, chose the HPV DNA test despite their lack of familiarity with HPV and linking a positive result with infidelity, immorality and degenerative behaviour (Brown et al., 2007).

HPV DNA testing as a primary screening test is proposed to reduce the number of Pap smears conducted in organised screening programs; however, there has been little research about women's acceptance of HPV DNA testing as a replacement for the Pap smear. One such study has shown that the majority of older women, between 50 and 80 years of age, would have HPV DNA testing (64%) with a further 17% on physicians' recommendation but despite having a negative Pap smear and HPV DNA result would continue with annual Pap smears, regardless of physician recommendations (Huang et al., 2008). There were no predictors associated with this

finding and also of note was that women under 65 years of age would want more frequent Pap smears (between 2 and 4 per year) if they received a positive HPV DNA test result (Huang et al., 2008). These findings indicate the need for more extensive research and community education to assist women to feel comfortable with changes to screening tests in the future, especially as policy changes can be viewed as being motivated by economic factors rather than science (Smith, French and Barry, 2003).

In addition to the psychological impacts of receiving an abnormal HPV DNA test, the actual process for collecting HPV DNA is similar to the Pap smear procedure, therefore the same barriers, such as embarrassment, discomfort and familiarity of the provider, remain important when considering acceptability of this test.

There has been increasing research into women's acceptability of self collected tampons or swabs for HPV DNA testing given women's dislike of the Pap smear, which results in some women not participating in screening (Morris and Rose, 2007). Women's acceptability and satisfaction with self collected HPV DNA tests both within the clinical setting and at home, have found high levels of acceptance, satisfaction, comfort and ease of use and low levels of pain and embarrassment (Anhang et al., 2005; De Alba et al., 2008). The use of self collected samples has been explored amongst women, who do not respond to invitations to screen in national population screening programs, to determine their likelihood of participating in cervical screening if an alternative testing method were available. In these studies, women were more likely to return a self collected sample when invited to do so than return for a Pap smear if they received a recall letter; however response rates overall to these strategies were moderate 32–34% (Sanner et al., 2009; Bais et al., 2007). Despite this, the participation of these women, who are at increased risk of cervical cancer given they were not having regular Pap smears, was considered beneficial in both studies.

There have been differing findings about women's preference for self collected versus clinician collected samples. Women's preference for self collection was low (32%) in a study of low income women in the USA, although they were positive about the test; but the converse was found in a British study where 73% of women preferred self collection (Anhang et al., 2005; Waller et al., 2006). When

considering the acceptability of either Pap smears or HPV DNA testing by women, the harms and benefits associated with the use of these tests within an organised screening program must also be considered. Whilst both tests have the benefit of preventing cervical cancer through the identification of precancerous abnormalities, there are a number of harms that need to be considered in this changing context.

Due to the expected high positive rate and in view of the transient nature of HPV infection in young women, the benefits of HPV primary screening are questioned in view of the potential harms, namely, the uncertain psychological impacts of a positive result and the potential for unnecessary intervention and over-treatment of women who are HPV DNA positive but cytologically negative (Goldie, Kim and Wright, 2004). In addition, the harms associated with the detection of transient HPV infection in young women also needs to be taken into account given the International Agency for Cancer Research in 2005 reported there is potentially more harm than benefit in screening young women under 25 years of age, as there is evidence of poorer reproductive health outcomes in young women following treatment for cervical abnormalities detected by screening (IARC, 2005; Kyrgiou et al., 2006). In addition, there is a lack of evidence that cervical screening has any benefit in reducing the incidence of cervical cancer amongst women less than 25 years at a population level (Canfell et al., 2004; Sasieni, Adams and Cuzick, 2003). These issues need to be taken into account when considering the acceptability of screening, whatever method is used for the secondary prevention of cervical cancer.

With the recent development of a primary method of cervical cancer prevention, the acceptability of HPV vaccination has been widely researched and is discussed in the next section.

2.5.3 HPV Vaccination

Since a prophylactic vaccine against oncogenic HPV was first proposed, there has been an ‘explosion’ in funding for vaccine-related research (Sturm, Mays and Zimet, 2005). This research has primarily focused on vaccine development, although increasingly studies have been undertaken to investigate acceptance of and attitudes towards HPV vaccination within the community. The majority of studies described in this section are Australian studies given their relevance to this study.

These studies have been undertaken to explore vaccine acceptability and to investigate whether poor knowledge of HPV and the association between sexual activity, a sexually transmitted infection (HPV) and cervical cancer influences vaccine uptake. The importance of women and health providers having access to accurate information regarding these issues to inform decision-making regarding consent for vaccination, cervical screening and follow-up procedures is widely recommended in the literature (Garland, Skinner and Brotherton, 2011b; Waller et al., 2005; Kahn et al., 2003; Marlow, Waller and Wardle, 2007).

The success of HPV vaccination as a primary prevention strategy against cervical cancer is dependent upon vaccine uptake in the population. Vaccine uptake in turn, is dependent upon young women's acceptability of the vaccine and as the vaccine is anticipated to have the greatest impact if given to girls pre-sexual debut, their parents' attitudes are important given they are required to consent for their daughters to be vaccinated (Sturm, Mays and Zimet, 2005; Mays, Sturm and Zimet, 2004; Zimet et al., 2005b; Rosenthal et al., 2007; Katz et al., 2010).

A consistent finding across all studies, irrespective of the setting, is high acceptance and positive attitudes towards HPV vaccination (McClelland and Liamputtong, 2006; Kahn et al., 2007; Marshall et al., 2007; Pitts et al., 2007; Cooper Robbins et al., 2010b; Dempsey et al., 2006; Gerend, Lee and Shepherd, 2007; Zimet et al., 2005b). The impact of parental age, socioeconomic status, gender, race/ethnicity and other socio-demographic characteristics on knowledge of HPV or attitudes to the HPV vaccine were not found to be of statistical significance in the majority of these studies, which may be due to study limitations, such as convenience sampling, poor response rates or limited sample size. In a population-based study of Victorian women aged 18–61 years, there was a significant positive correlation between a respondent's age and her attitude towards vaccination (Pitts et al., 2007). Significant differences were also found between six broadly defined ethnic and cultural groups in this study, with less positive attitudes towards vaccination expressed by Asian and/or Middle Eastern women (Pitts et al., 2007). Aboriginal and Torres Strait Islander women were not identified specifically in the findings of this study.

However, these findings also suggest there are multiple factors involved in vaccine acceptability and that decision-making is a complex process that is not

standard amongst individuals (Cooper Robbins et al., 2010b; Katz et al., 2010). With the implementation of the NHPVP, there has been extensive HPV vaccine research conducted in Australia with girls, parents, women of all ages and health providers. A number of these studies have explored the factors associated with attitudes and decision-making processes about vaccination, including whether suppressing the association between cervical cancer and a sexually transmitted virus is beneficial to acceptability. In an on-line survey of young women aged 18–26 years, 94% and 98% of women had heard of HPV and the HPV vaccine, respectively; however most were unsure that HPV was linked to cervical cancer (Shand, Burney and Fletcher, 2010). This limited knowledge was also found amongst parents of girls involved in school-based vaccination in NSW who responded 'don't know' to many items about HPV and HPV vaccination knowledge when interviewed, despite most consenting for their daughters to be vaccinated against HPV (Cooper Robbins et al., 2010b). However, poor knowledge has not been found to decrease acceptance of the HPV vaccine, nor consent and completion of the three dose regimen (Juraskova et al., 2011; Cooper Robbins et al., 2010b; McClelland and Liamputtong, 2006).

A model to assist in identifying and understanding vaccine uptake and completion has been proposed following a systematic review of the literature (Katz et al., 2010). This model identifies structural and social factors, such as cost, access, socio-demographic factors and past vaccination related behaviours, caregiver factors, including health beliefs, healthcare utilisation and relationship with child, individual adolescent factors including relatedness to care-giver, developmental maturity, health beliefs, healthcare utility, knowledge and self-efficacy and adherence behaviours (Katz et al., 2010).

Health beliefs have been the focus of a number of studies in the Australian setting. Perception of risk, especially how HPV was transmitted, was found to be lower in women with lower levels of HPV knowledge, and amongst those with no personal experience of HPV (McClelland and Liamputtong, 2006). In a study evaluating the Health Belief Model (HBM) for its ability to predict young women's intent, perceived barriers and benefits were significant predictors of intent to have the HPV vaccine and subsequent uptake (Juraskova et al., 2011). This study conducted in the first phase of the NHPVP of first year university students in Sydney, identified receiving information about HPV and cervical cancer and knowing someone with

cervical cancer or another cancer, was also associated with the intention to be vaccinated, in this convenience sample of well educated young women (Juraskova et al., 2011).

These authors also investigated whether providing information about the vaccine primarily as a preventative for cervical cancer or including messages about the prevention of genital warts had an influence on young women's intention to have the vaccine. The sample was randomly assigned to receive a leaflet about how the vaccine protected against cervical cancer only or alternatively about both cervical cancer and genital warts. The authors concluded perceived benefits and severity scores were higher in the group receiving the additional information about genital warts and that including information about HPV as a sexually transmitted infection did not influence vaccination intention in this sample (Juraskova et al., 2011). Studies with young women indicate attitudes and acceptance towards vaccination are not affected by making explicit the link between sexual activity, HPV and cervical cancer; however older women, from diverse cultural backgrounds participating in focus groups in Victoria, thought it best to keep the fact HPV was a sexually transmitted infection secret. (Rosenthal et al., 2007; Juraskova et al., 2011; McClelland and Liamputtong, 2006).

Sexual health and the association of HPV with cervical cancer has been notably absent from Australian newspaper articles and public health messages before and after the implementation of the NHPVP media, with the majority of articles focusing primarily on cervical cancer prevention (Juraskova et al., 2011; Cooper Robbins, Pang and Leask, 2011). Comfort levels in discussing sexual matters differ in the findings of studies with providers, parents and girls and the absence of fathers in decision-making about HPV vaccination was noted in one study (Skinner, Kang and Rosenthal, 2007; Brotherton, Leask, et al., 2010; Cooper Robbins et al., 2010b). It is reassuring; however, that concerns that the vaccination of young girls against HPV will lead to increased sexual behaviour, is not of great concern in the Australian setting, despite this being an issue identified in overseas studies (Marshall et al., 2007; Pitts et al., 2007; Garland, Skinner and Brotherton, 2011b; Olshen et al., 2005).

A consistent finding across all studies is that the recommendation or positive opinion of respected and trusted persons, including parents and authorities such as

teachers, health providers and the health department, is influential in women's decision making about the HPV vaccination (Gerend, Lee and Shepherd, 2007; McClelland and Liamputtong, 2006; Rosenthal et al., 2007; Pitts et al., 2007; Cooper Robbins et al., 2010b; Cooper Robbins et al., 2010a; Cooper Robbins et al., 2010c). This highlights the importance of providing up-to-date information about cervical cancer, HPV and the HPV vaccine to these trusted sources of advice (Tan, Farrell and Allen, 2010; Garland, Skinner and Brotherton, 2011b; Brotherton, Leask, et al., 2010; Cooper Robbins et al., 2010a; Marshall et al., 2007).

Mass media is the most common source of consumer information about HPV and the vaccine in the Australian setting (Pitts et al., 2007; Rosenthal et al., 2007; Juraskova et al., 2011). Increased knowledge regarding HPV was found in an American study following intensive media coverage of the vaccine, before and after it received approval by the Food and Drugs Administration (Kelly et al., 2009). As previously mentioned, there are gaps in the messages conveyed through the media given their primarily role is not health education and therefore educational campaigns need to convey messages related to the transmission of HPV, what the vaccine protects against and the importance of cervical screening, irrespective of vaccination status, if these deficits are to be addressed (Garland, Skinner and Brotherton, 2011b; Cooper Robbins, Pang and Leask, 2011; Kelly et al., 2009). The information sought by the community regarding HPV vaccination includes potential side-effects and risk associated with vaccination, efficacy and whether the vaccine was life-saving, the duration of protection, whether males should be vaccinated and if the vaccine was safe (Rosenthal et al., 2007; Cooper Robbins, Pang and Leask, 2011; Marshall et al., 2007).

The conclusions from studies conducted overseas are largely consistent with the findings of Australian studies. One of the main factors associated with acceptance of HPV immunisation amongst mothers of teenage girls is perception of risk (Lazcano-Ponce et al., 2001). Mays et al, (2004), argue that for less familiar infections, such as HPV, comprehensive educational campaigns about the specific protective benefits of vaccines for sexually transmitted infections are needed to enhance parental acceptance, especially as it is parents who play a key role in consenting to their children's participation in HPV vaccination (Pitts et al., 2007; Zimet, 2005a).

Another key aspect specific to the HPV vaccine that appears poorly understood is that maximal efficacy is achieved if the vaccine is given to young women pre-sexual debut, which has had implications for the school-aged cohort in terms of vaccine acceptability by parents and their daughters (Zimet, 2005a; Pitts et al., 2007). This needs to be understood by Australian young women aged 18–26 years who had access to HPV vaccination through general practice until 2009 as they may have been exposed to HPV 16 or 18 prior to being vaccinated (NCIRS, 2006b). Vaccinated young women and women throughout Australia need to be aware of the importance of regular participation in cervical screening as the vaccine will not impact on pre-existing HPV infections and does not protect against all types of oncogenic HPV (NCSP, 2007a; Brotherton, 2007; NCIRS, 2006b). This has prompted the NCSP, the NHVP and the National Centre for Immunisation Research and Surveillance to release statements promoting cervical screening on all HPV vaccination information and pharmaceutical companies marketing HPV vaccines in Australia have followed suit (NCSP, 2007b; NCIRS, 2006b).

Concerns have also been raised that the women least likely to access vaccination are those who are also less likely to access cervical screening (IARC, 2005). This has led to recommendations for future research that focuses on women who are less likely to participate in cervical screening and who are therefore at higher risk of cervical cancer (Brewer and Fazekas, 2007; Marlow, Waller and Wardle, 2007).

The majority of studies conducted to date have been undertaken in developed countries or in metropolitan areas; however it is well documented age, racial, cultural, accessibility and socio-economic factors are significantly associated with an increased risk of cervical cancer (Brewer and Fazekas, 2007; IARC, 2005; Homewood, Coory and Dinh, 2005). Brewer and Fazekas, (2007), contend studies exploring vaccine acceptability amongst populations most affected by cervical cancer are required to ensure the existing disparities in health care access do not increase with the introduction of HPV vaccination.

There is increasing information in the Australian setting regarding knowledge and awareness of HPV and its link to cervical cancer and attitudes towards HPV vaccination; however gaps remain particularly in relation to Aboriginal and Torres Strait Islander peoples' views and those of people from culturally and linguistically

diverse backgrounds (Heffernan, 2007). This research is necessary to determine the potential impact of the vaccine and to identify future policy and strategies to further reduce cervical cancer incidence and mortality across the entire population. It is not known if women least likely to access cervical screening have less favourable attitudes towards HPV vaccination or whether they are less likely to consent to their daughters being vaccinated. Research is needed to further explore this aspect of HPV immunisation amongst Queensland women, particularly those who are less likely to participate regularly in cervical screening.

2.6 SUMMARY AND IMPLICATIONS

Cervical screening programs need to be evaluated because the addition of HPV vaccination will make the existing approach of high-frequency screening by cytology too costly and inefficient for most public health budgets (Franco et al., 2006). Empirical data will not be available for some time to inform policy makers and health professionals involved in such evaluations and mathematical modelling is underway to provide local insight into the impact of the vaccine and changes to cervical screening policy. In addition to modelling, behavioural research is required to enable greater understanding of the information needs and attitudes of women given the vast changes in our understanding of cervical cancer, the natural history of HPV and the advent of new technologies that have occurred over the past decade.

As evident in studies conducted in Australia and overseas, women's knowledge of cervical cancer prevention strategies and the link between cervical cancer and HPV is limited. There is also limited data to assist policy makers and public health educators assess the impacts and outcomes of existing cervical cancer prevention strategies and inform future strategies to address the needs of women in Queensland. By specifically investigating Queensland women's knowledge of HPV and cervical cancer and knowledge and attitudes about cervical screening and the HPV vaccine, knowledge deficits and barriers to screening can taken into account when decisions about communication strategies and changes to the NCSP screening policy are made. This will inform the development of targeted strategies that aim to increase rates of cervical screening participation and disseminate new information and knowledge about cervical cancer/screening, HPV and HPV vaccination to further reduce cervical cancer incidence and mortality in Queensland. In addition, understanding what women currently perceive about cervical cancer prevention strategies will assist in

developing communication strategies to assist women to understand and accept anticipated changes to a well established screening program that has remained unchanged in Australia for over two decades.

To address the lack of local information about Queensland women's knowledge and attitudes towards cervical cancer prevention strategies, this study utilised quantitative and qualitative methods of inquiry. This enabled exploration of socio-demographic and personal factors impacting on women's knowledge and beliefs about cervical screening and HPV vaccination and provided insight into their beliefs and attitudes about primary and secondary cervical cancer prevention strategies, thereby adding to existing research in the Australian context.

The methods used to conduct this study, which incorporate both quantitative and qualitative approaches, are described in the following chapter.

Chapter 3: Overarching Research Design

This chapter describes the design adopted by this research to achieve the aims and objectives stated in Section 1.3 of Chapter 1, namely:

- To determine what Queensland women know and say about:
    - cervical cancer/screening and their beliefs about and attitudes towards Pap smears,
    - human papillomavirus (HPV) and the HPV vaccine and their attitudes towards the vaccine.
- To identify where Queensland women get their health information from and the most effective methods they recommend for communicating and promoting information to women should changes be made to the NCSP.

The methodology used in the study and when each phase was implemented is described in Section 3.1, which is followed by a description of the conceptual framework underpinning this study in Section 3.2. The ethical considerations of the research are discussed in the final section of this chapter (Section 3.3).

3.1 METHODOLOGY AND RESEARCH DESIGN

3.1.1 Methodology

This research was a descriptive-exploratory study that incorporated a combination of qualitative and quantitative methods (methodological triangulation). Methodological triangulation was adopted as quantitative data provides good descriptive data about the research topic of inquiry whilst qualitative methods assist to explore and explain the subject matter in detail (Ulin, Robinson and Tolley, 2005). The combination of methods aimed to provide a more complete picture than the use of one approach in isolation and be complementary to each other (Ulin, Robinson and Tolley, 2005).

3.1.2 Research Design

Phase 1 of the project used an inductive quantitative approach incorporating a computer-assisted telephone interview (CATI) survey of women across Queensland

(Appendix A). This was conducted in the formative phase of the study to provide information about socio-demographic and structural differences in knowledge and attitudes between subgroups, for example, older women compared to younger women or by screening status and to guide the topics of inquiry in the qualitative phase.

Phase 2 utilised focus groups to gather in-depth information about women's knowledge, awareness and acceptance of cervical cancer prevention strategies and ascertain the sources women used and recommended for obtaining and disseminating health information and further explore and explain the findings of Phase 1. A qualitative approach was incorporated into this study to produce information rich data and answer questions not suited to the structured format of the telephone survey, particularly those relating to sensitive subjects for example, perceptions about barriers to screening (Liamputtong and Ezzy, 2005).

3.2 THE CONCEPTUAL FRAMEWORK

The Health Belief Model (HBM) guided the process of inquiry for the qualitative component of this study. The HBM is one of a number of social cognition models (SCMs) that has been widely adopted by researchers attempting to explain health related behaviour and was developed by a group of social psychologists in the 1950s (Roden, 2004; Rosenstock, 1974; Murray and McMillan, 1993).

Health related behaviours are activities undertaken to prevent or detect disease or improve one's health or well-being (Connor and Norman, 2005). SCMs provide a basis for understanding factors that determine behaviour or lead to behaviour change and assist in targeting interventions that might facilitate change. Six factors have been postulated to influence health behaviours, namely:

1. accessibility to services,
2. attitudes to health,
3. perceptions of disease threat,
4. knowledge about disease,
5. social networking characteristics, and,
6. demographic factors (Connor and Norman, 2005).

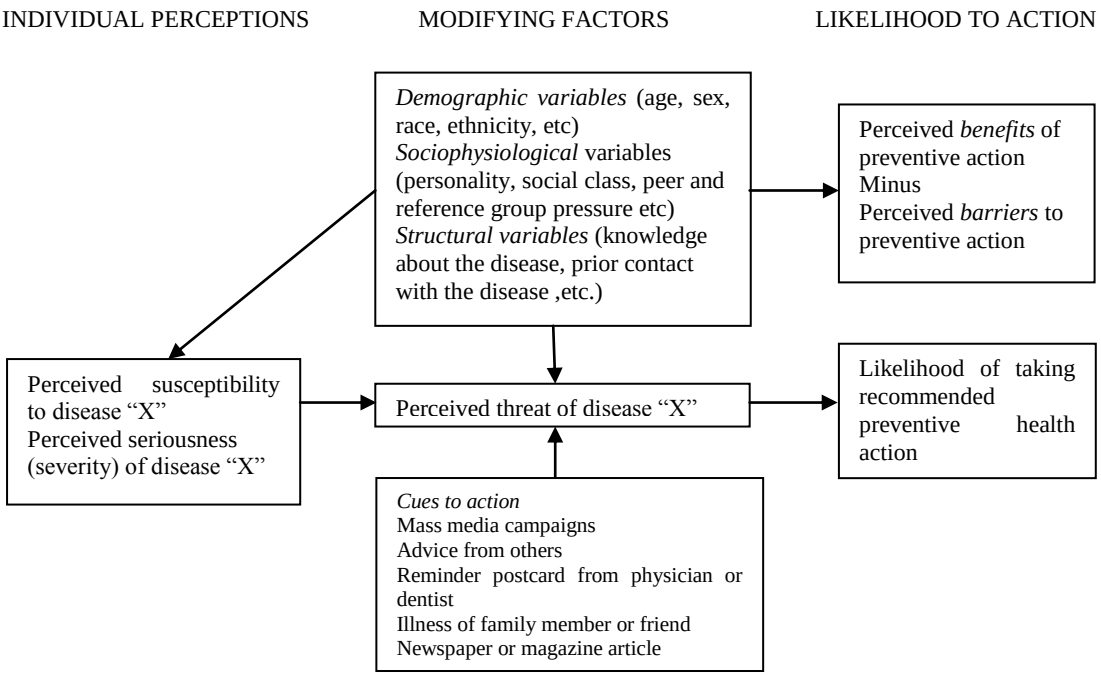

Figure 3.1. The Original Health Belief Model (Rosenstock, 1974)

Factors 2–5 are social-cognitive factors, of interest to psychologists attempting to develop a greater understanding of factors that were open to change and may be influenced to promote behaviour change (Connor and Norman, 2005). Early work was related to the public acceptance of programs to screen for disease, such as tuberculosis, or immunise against infections, for example, polio and influenza (Rosenstock, 1974; Burak and Meyer, 1997; Rimer and Glanz, 2005). The HBM model was based on Kurt Lewin's value-expectancy theory and was originally focused on two aspects thought to influence health behaviour in response to the threat of illness, namely perception of illness threat and evaluation of behaviours to counteract this threat (Rosenstock, 2000; Rimer and Glanz, 2005; Connor and Norman, 2005). The perception of threat was based on two beliefs, perceived susceptibility and perceived severity to the disease of concern (Connor and Norman, 2005).

As outlined in Figure 3.1, perceived susceptibility to and perceived seriousness of disease and the benefits of taking action, perceived barriers and cues to action were the original key components of the HBM (Rimer and Glanz, 2005; Rosenstock, 1974). Perceived susceptibility to disease is based on the individual's subjective risk they are at risk of disease. When applied to screening, the individual also must perceive they are at risk even in the absence of any symptoms (Rosenstock, 1974).

Perceived severity is based on beliefs about the seriousness of contracting an illness and potential consequences to personal and other factors in a person's life including, for example, the impact on family and income (Rosenstock, 1974; Rimer and Glanz, 2005). Both susceptibility and severity have a strong cognitive component that is partly dependant on knowledge (Rosenstock, 1974). Perceived benefits relate to beliefs about the effectiveness of a particular action in reducing the threat of the disease or the consequences and seriousness if the disease occurs, whilst perceived barriers include both material and psychological aspects of taking action including cost and access issues, embarrassment and pain (Roden, 2004; Rimer and Glanz, 2005). Cues to action are those factors that prompt or stimulate health behaviours and can be internal or external events (Burak and Meyer, 1997; Rimer and Glanz, 2005). External factors include the impact of mass media campaigns or receiving a recommendation or reminder letter from a health professional (Rosenstock, 1974).

The HBM was further expanded over time until it was comprised of six main constructs thought to influence people's decisions about participating in screening and preventative health activities and three modifying variables including demographic, psychosocial and structural variables (Rimer and Glanz, 2005; Murray and McMillan, 1993). Self-efficacy was the sixth construct added to the model by Bandura (1977), and relates to an individual's confidence to take action and the conviction that they are able to successfully carry out the behaviour (Rosenstock, 2000; Rosenstock, 1974). Bandura (1977), contends that people avoid threatening situations due to fear they will not cope well but will involve themselves in activities even if they consider them intimidating, if they judge themselves capable of handling the situation. Self-efficacy was added to the model as it was found to be a key predictor of health behaviours and would therefore add to the predictive power of the HBM (Bandura, 1977; Rosenstock, Strecher and Becker, 1988).

These beliefs are influenced by modifying factors including demographic, psychosocial and structural variables. Demographic variables include socio-demographic variables such as educational attainment, psychosocial variables, which include locus of control and emotional control, whilst knowledge of and contact with the disease are structural variables that impact on beliefs (Murray and McMillan, 1993). These modifying factors influence an individual's likelihood of taking action

based on their perceived benefits of taking that action, minus the perceived barriers to action.

A number of limitations of the HBM have been identified, including the absence of normative influences such as social pressures/desirability and the lack of a measure of behavioural intention, which has been found to one of the strongest predictors of behaviour (Carpenter, 2010; Abraham and Sheeran, 2005). Therefore, the HBM does not directly address the issue of translating intentions into actions (Connor and Norman, 2005). In addition, there is limited evidence of the predictability of the main constructs of the model to lead to behaviour change, which has been attributed in part, to difficulties in comparing studies based on the HBM. Constructs have been construed and measured in different ways due to lack of clarity of some constructs, for example, cues to action, and the lack of hierarchal or temporal relationships between cognitions (Yarbrough and Braden, 2001; Tanner-smith and Brown, 2010; Abraham and Sheeran, 2005). Two studies in which the HBM's ability to predict intentions to participate in cervical screening or receive the human papillomavirus (HPV) vaccine and vaccine uptake behaviour have confirmed that the constructs of the model have limited impact on intention and behaviour (Juraskova et al., 2011; Burak and Meyer, 1997). A meta-analysis conducted in 1984 found evidence for the predictability of the four major constructs of the model, perceived susceptibility/ severity/ benefits and barriers; however this review has been criticised for the methods used to measure predictability and subsequent meta-analysis have revealed conflicting findings (Abraham and Sheeran, 2005; Janz and Becker, 1984). The HBM also fails to account for behaviours that are influenced by social and affective factors such as socio-economic costs (Tanner-smith and Brown, 2010; Abraham and Sheeran, 2005).

Despite these limitations, the HBM does specify a discrete set of common sense cognitions, which have been identified as useful for examining antecedents of self-efficacy and intention rather than predictors of behaviour and its applicability as an essential reference point in the development of messages to improve knowledge and change beliefs is acknowledged (Abraham and Sheeran, 2005; Nutbeam and Harris, 2004). This model has been adopted and found to be relevant in both quantitative and qualitative studies aiming to explore knowledge and beliefs about cervical cancer prevention behaviours and continues to be used in descriptive studies

(Waller, McCaffery and Wardle, 2004a; Brewer and Fazekas, 2007; Murray and McMillan, 1993; Jirojwong and Manderson, 2001; McClelland and Liamputtong, 2006; Juraskova et al., 2011; Dempsey et al., 2006).

The HBM was adopted for the purposes of this study as it has been utilised extensively in both quantitative and qualitative cervical cancer prevention studies and enabled reflection of the findings of this study with those found in other studies conducted both locally and overseas (Waller, McCaffery and Wardle, 2004a; Brewer and Fazekas, 2007; Jirojwong and Manderson, 2001; McClelland and Liamputtong, 2006; Juraskova et al., 2011; Dempsey et al., 2006; Cooper Robbins et al., 2010b). In addition, the constructs of the HBM provided a useful framework on which to develop the topic guide for the focus groups, which aimed to assess women's beliefs, knowledge and attitudes towards cervical cancer/screening, HPV and the HPV vaccine. The relationship between the research questions in this study and the constructs of the HBM are outlined in Table 3.1.

The key constructs of the HBM were considered highly relevant to cervical cancer prevention health behaviours as they enabled the exploration of women's beliefs about their perceived susceptibility to and severity of cervical cancer in the context of a setting in which incidence and mortality rates have decreased to such low levels that women are unlikely to have extensive experience with family or friends affected by this disease. In addition, there have been limited studies exploring what Queensland women perceive about the benefits and barriers of cervical screening and their attitudes towards vaccination and what they perceive as cues to promote their participation in cervical cancer prevention strategies. This study aimed to assess knowledge, attitudes and beliefs to inform future health promotion strategies largely aimed at disseminating changes to the screening policy and National Cervical Screening Program (NCSP), not measure women's intention to participate in screening or vaccination.

The HBM was therefore considered an appropriate model for the purposes of this study to explore Queensland women's attitudes, beliefs and knowledge about cervical cancer prevention to inform future health promotion strategies in light of the anticipated changes to cervical screening in the near future, following the Renewal of the NCSP.

Table 3.1: Relationship of Research Questions to the HBM and Overarching Focus Group Questions

Research Questions	HBM Constructs	Question
What do women know about cervical cancer/screening and what are their attitudes towards Pap smears?	Self-efficacy	What do you think of the following statement: "Good health is largely a matter of good luck"
	Perceived susceptibility to disease	What do you think causes cancer of the cervix?
		Do you think every woman has the same risk of getting cancer of the cervix?
	Perceived seriousness of disease	If a woman gets cervical cancer, is there a cure? Do you think it would have a big impact on a woman's health?
	Perceived benefits of taking action	What do you know about Pap smears?
	Perceived barriers to action	What do you think prevents some women from having Pap smears or putting them off?
	Cues to action	What do you think prevents some women from having Pap smears or putting them off?
		Hypothetical - If there was a test that you could do at home, say a tampon or swab you could insert yourself and send in the mail – do you think women who don't go for Pap smears now might do it?
What do Queensland women know about HPV and what are their attitudes towards the cervical cancer/HPV vaccine?	Perceived susceptibility to disease	What do you know about human papillomavirus or HPV?
	Perceived benefits of taking action	What do you know about the new vaccine for preventing cancer of the cervix?
	Cues to action	What do you think would prompt a woman to agree for her daughter to have the vaccine or to have the vaccine herself?
What do they women perceive as the most effective methods of communicating and promoting new information should changes be made to the NCSP	Cues to action	Where do you get your health information from?
		The QCSP has developed a number of ways to provide information about HPV and cervical cancer –If there was new information we wanted to provide to women - what do you think is a good way to do this?

3.3 ETHICS

3.3.1 Ethical Approval

This research involved the participation of humans and was undertaken in accordance with the National Statement on Ethical Conduct in Research Involving Humans and the Australian Code for Responsible Research to ensure ethical conduct in all aspects of the study research (NHMRC, 2007a. 2007b). Ethical approval for the use of data from the CATI survey, which was commissioned by Queensland Health, was sought and the research was conducted in accordance with the Queensland Health Research and Ethic Unit guidelines and policies and the Public Health Act 2005. Ethical approval for the study was granted by the Queensland University of Technology University Human Research Ethics Committee – approval number 0800000366.

3.3.2 Main Ethical Considerations

Consent

Verbal consent was obtained from women participating in the CATI survey by the agency conducting the survey on behalf of Queensland Health. Women who wished to check the authenticity of the survey were given contact details for the Queensland Cervical Screening Program (QCSP) and one woman called to verify the authenticity of the study. Women were also offered additional written information regarding the survey but this was not required.

Written consent was sought from women participating in the focus groups. An information sheet was provided with the consent form to inform women about the study and advise them participation was voluntary and they had the right to withdraw from the study at any time and could decline to answer any questions (Appendix B, Appendix C). Verbal consent was sought from women to audiotape the focus groups.

On a few occasions, women raised concerns about the consent process. One woman was unhappy about the statement in the consent form "understand that you are free to withdraw at any time, without comment or penalty" as she felt this was patronising but still signed the form. Two women in one group (an older woman and her daughter) did not want to sign the consent form or participate in the focus group (no reason sought or given), but wished to observe and the other women in the group

did not object so they observed the focus groups and then actively participated in the information session.

In one of the first groups conducted, a woman arrived late and did not hear the information about the audio-tape recording and much later, on realising this, got up from the table and left the group. The researcher spoke with her later and apologised and reassured her about the confidentiality of the recordings and data and she agreed for her input to be included if no names were used. She disclosed she had escaped a domestic violence situation and was in hiding, which was why she reacted the way she did. This issue informed the issue of late comers in future focus groups. It was not often but the group organiser or the observer, if present, was asked to give late comers the forms to complete and advise them about the recording prior to joining the group. This worked well and no further issues occurred with the recording of focus groups.

Confidentiality and Storage of Data

Survey data was provided electronically to the researcher from the CATI facility and was stored on the Queensland Health secure password protected server with daily back-up to a secure network at Queensland Health. The network drive at Queensland Health is part of a secure network with a firewall and password authentication. The database did not contain any identifying information. Analysis was also undertaken at the researcher's home and data and findings were stored on a secure password protected drive.

There were no names or identifying information reported in focus group findings. When women referred to potentially identifying information in transcripts about their locations for example, this was de-identified also. Women's names were recorded on the consent forms, which were kept separate in locked filing cabinets to the questionnaires they completed pre focus groups and those who wanted to receive a report of the findings provided personal details, which were also kept separate from the other study information.

Qualitative data was recorded using audiotapes, which were transcribed and together with written notes taken during focus groups and survey responses were entered into NVivo by the researcher and five research assistants. Each research assistant signed a confidentiality agreement prior to transcribing or entering data

(Appendix D). This information was stored on the researcher's personal computer on a secure password protected drive. Consent forms were scanned and stored electronically by the researcher and stored on the Queensland Health secure password protected server.

All paper based information was stored in a locked cabinet in the researcher's office, which is located in a secured building. Paper-based information was destroyed through commercial shredding as soon as possible once the information was recorded electronically in accordance with Queensland Health's guidelines for the storage and destruction of confidential research information.

All publications and information released by the researcher is in the form of aggregated findings with the exception of de-identified quotes used to reinforce the outcomes of focus groups. These quotes do not contain any identifying information.

Dissemination of Findings

Research outcomes will be disseminated in the form of peer reviewed journal articles and will be also published and available in the form a doctoral thesis. Presentations have been made at national and international conferences and have been communicated to national and jurisdictional cervical screening programs and key stakeholders of the QCSP, including the Cancer Screening Services Branch Consumer Reference Group, the QCSP Quality Management Committee, Family Planning Queensland and Women's Health Queensland Wide (Appendix E).

A report on the findings of the focus groups was developed for participants and was disseminated to them prior to any written publication of focus group findings in the public domain (Appendix F). All publications arising from the research will be accessible through the lead research agency, Queensland University of Technology. A media release will be provided at the conclusion of the project to ensure the wider public has access to the key findings of the research.

Chapter 4: Research Design Phase 1

This chapter describes the design adopted by this research to achieve the aims of Phase 1 of the study. Section 4.1 discusses the aims of Phase 1; Section 4.2 details the participants in the study; Section 4.3 lists the instruments used in Phase 1 and justifies their use; Section 4.4 outlines the procedures used and the timeline for completion of Phase 1; and Section 4.5 discusses how the data was analysed.

4.1 RESEARCH QUESTIONS AND HYPOTHESES

The research questions to be addressed in Phase 1 of the study were:

- What do Queensland women know about cervical cancer/screening and does this differ by socio-demographic factors or cervical screening history?
- How many Queensland women have heard of human papillomavirus (HPV) and does this differ by socio-demographic factors, cervical screening history or cervical cancer/screening knowledge?
- What do Queensland women know about HPV and does this differ by socio-demographic factors, cervical screening history, awareness and attitudes?
- How many Queensland women are aware of the HPV vaccine, where did they hear about it and does awareness differ by socio-demographic factors, screening history, cervical cancer/screening knowledge or awareness?
- What are Queensland women's attitudes towards HPV vaccination and does this differ by socio-demographic factors, screening history, cervical cancer/screening knowledge or awareness?

The hypotheses tested were:

- H^1: Cervical cancer/screening knowledge differs between Queensland women from different socio-demographic groups and screening history groups.

- H^1: HPV awareness differs between Queensland women from different socio-demographic groups and screening history groups and by cervical cancer/screening knowledge.
- H^1: HPV knowledge differs between Queensland women from different socio-demographic groups and screening history groups and by cervical cancer/screening knowledge, awareness of the HPV vaccine and attitudes towards vaccination.
- H^1: Awareness of the HPV vaccine differs between Queensland women from different socio-demographic groups and by screening history groups and by knowledge and awareness.
- H^1: Attitudes towards the HPV vaccine differs between Queensland women from different socio-demographic groups and by screening history, knowledge, awareness or attitudes.

The variables collected in Phase 1, their relationship with the research questions and how they were measured are outlined in Appendix G.

4.2 PARTICIPANTS

Women aged 20 to 69 years who had not had a hysterectomy were invited to participate in the survey. These criteria were used as this group of women are the primary target population for the National Cervical Screening Program (NCSP) in Australia. An additional eligibility criterion was that women were required to be resident in Queensland.

The survey sample frame was obtained from the Association of Market and Social Research Organisations (AMSRO) Random Digital Dialling (RDD) sample database. RDD has been reported to select reasonable random samples as unlike other methods, such as Electronic White Pages listings, allows contact with people who have unlisted or recent connections (Choi, 2004; I-View Pty Ltd, 2008). Those with unlisted numbers have been reported to be more likely to be living in metropolitan areas, be single, younger and be current smokers (Dal Grande, Taylor and Wilson, 2005).

4.2.1 Sample Size

A total sample size of 1000 women was required to detect a clinically significant minimum meaningful difference (Battistutta, 2010b) of 1.5 (where the anticipated difference was 2) in mean cervical cancer/screening knowledge scores by age, locality and SES as these were key factors of interest as cervical screening participation rates differ by these factors in most Australian jurisdictions (AIHW, 2011). Clinical significance relates to the applicability of the research findings to the practical context, which in this case, is cervical cancer prevention (Battistutta, 2010b). This difference was determined from previous studies conducted by Pitts and Clarke, (2002), in which the mean cervical cancer/screening knowledge score was 13.49 (SD 3.68) and Hancock et al, (1996), who determined a 10% difference in knowledge was significant when studying knowledge of cancer risk reduction practices in NSW. A difference of 1.5 also reflects roughly one third to one half of a standard deviation of previous knowledge scores which is commonly associated with a meaningful difference. The sample size was based on a type I error rate of 5% (two-tailed) and a type II error rate of 10% (power = 90%).

The sample size was also inflated to allow for a response rate of 70% with a prediction that approximately 300 women would refuse to participate. The response rate of 70% was determined from the participation rate achieved in a previous computer-assisted telephone interview (CATI) survey conducted by the QCSP in 2005 (CSSU, 2005). Sample size calculations for HPV knowledge and knowledge and attitudes towards vaccination were undertaken but are not reported as smaller sample sizes were required to detect meaningful differences.

Some oversampling was undertaken to allow for meaningful comparisons by (socio-economic status) SES. An area defined as most disadvantaged under socio-economic indexes for areas (SEIFA) is deemed so if (among other things), it is comprised of many households with low income, many people with no qualifications, or many people in low skilled occupations (ABS, 2006b). To optimise the chance of measuring differences in knowledge amongst women by locality and socio-economic disadvantage, the sampling strategy set quotas to take quintiles 1 and 2 samples to 25% each. Based on random sampling of the population it was expected 18.7% and 17.6% of the sample would be from these quintiles respectively. The sampling strategy aimed to generate a minimum of 10% of total

sample in quintile 4 and 10% in quintile 5. In doing so, this allowed statistical significance to be achieved on the knowledge index if there was a mean difference in knowledge of 1.5 where the anticipated mean difference was 2.

Respondents were assigned to each quota based on their location using their State Suburb Code, which was mapped to SEIFA categories by the CATI facility (ABS, 2006b). In addition, quota control was implemented with permission from the researcher during data collection to minimise skew towards older age groups as the CATI facility reported older women were participating at a higher rate than younger women and there was concern they would be underrepresented in the sample had this not occurred.

4.3 INSTRUMENT USED: CATI SURVEY

A CATI survey was used as the data collection method as this provides ready access to a large sample including those living in remote and rural communities, access to instant results and is cost-effective and particularly useful for surveys in which sensitive topics are discussed (Choi, 2004; Smith et al., 2009; Dal Grande, Taylor and Wilson, 2005). Computerisation also facilitates data collection through randomisation of questions and response options, consistency checks and automatic question skips (Choi, 2004). The "Print Media and HPV Questionnaire" was the instrument used for the CATI survey and was originally designed to capture information for two purposes:

1. to inform an interim evaluation of the QCSP social marketing campaign, and,
2. to collect data for the purposes of this study.

The QCSP social marketing campaign named, "Cervical Screening Participation Project: Prompting Action" commenced in 2005 with a goal to increase participation in cervical screening of women aged 20–69 years in Queensland. The campaign was conducted over a three year period with the primary strategy being a social marketing campaign, which included both mass media and non mass media.

The campaign message was delivered in a targeted television advertisement that appeared in two media bursts in February/March 2007 and July/August 2007. The mass media evaluation survey was carried out to evaluate the effectiveness of

the television advertising component of the QCSP Social Marketing Campaign and assess women's awareness of campaign message/messages and women's intention to act, i.e. had they had or were they planning to have a Pap smear (QCSP, 2008). The timing of the CATI survey was influenced by the QCSP Social Marketing Campaign as it was scheduled to be conducted prior to a subsequent burst of television advertising.

To accommodate both purposes, the questionnaire therefore included a total of 91 questions:

- *general health (three questions not included in this study)*
- women's knowledge about cervical cancer/screening (nineteen questions)
- women's cervical screening history (five questions)
- *media recall and intent (eighteen questions not included in this study)*
- women's knowledge about HPV (thirteen questions)
- women's knowledge of and attitudes towards vaccines and the HPV vaccine (seventeen questions)
- behavioural and socio-demographic data (sixteen questions).

Most questions were designed to capture data for both purposes of the CATI survey. The "Print Media and HPV Questionnaire" dataset was separated upon receipt from the CATI facility and analysed separately for each purpose. Responses to general health and media recall questions (italicised) and four socio-demographic questions from the overall CATI survey were not included in the dataset for the purposes of this study. Sixty-six questions were specifically designed for the purposes of this study and are outlined in Appendix A.

These questions were informed by tools used in previous studies of cervical cancer/screening and HPV knowledge and attitudinal studies about HPV vaccination as outlined in Table 4.1 (Pitts and Clarke, 2002; Pitts et al., 2007; Kahn et al., 2003; Waller, McCaffery and Wardle, 2004a; Brabin, Roberts and Kitchener, 2007; Marlow, Waller and Wardle, 2007). Permission was sought and granted from Professor Pitts and Dr Kahn for the use of their instruments.

The instruments for assessing women's knowledge about cervical cancer/screening, HPV and the HPV vaccine and attitudes towards the HPV vaccine were modified slightly as follows:

- cervical cancer/screening knowledge items - modified from the items described by Pitts and Clarke (2002), by adding items used in recent, similar measures of cervical cancer/screening knowledge and specific questions about cervical screening recommendations in Australia (Marlow, Waller and Wardle, 2007).
- HPV knowledge items – one item was added and there were slight modifications to the wording of four items in the HPV knowledge scale developed by Kahn et al, (2003) as follows:
    - the 'Pap smear detects HPV' was modified to 'the Pap smear is a test for HPV' to reduce the clinical nature of this statement
    - 'HPV causes abnormal menses' was modified to 'HPV causes women to have abnormal periods' as menses is not a frequently used term amongst women in the Queensland setting
    - 'smoking increases chance of cancer' was modified to 'If you have HPV, smoking can increase your chance of cancer' as the researcher was specifically interested in women's views about smoking and its relationship with HPV and cancer rather than smoking more broadly
    - 'HPV goes away with the right treatment' was modified to 'women often clear HPV without treatment' as there was no measure in the original scale that assessed whether women thought it was possible to clear the virus spontaneously, which was deemed important by the researcher to assess.

The HPV vaccination attitude scale was constructed prior to the implementation of the National HPV Vaccination Program (NHPVP), therefore, inappropriate items were removed and the scale was made gender specific as the vaccine was only publicly funded for females (NCSP, 2007a; Pitts et al., 2007). This tool contained eight items relating to vaccination in general and six items relating to HPV vaccination.

Table 4.1 Content of Questionnaire and Sources Used

Research questions	Items in Survey Instrument	Source of Items
What do Queensland women know about cervical cancer/screening and does this differ by socio-demographic factors or cervical screening history?	• Cervical cancer/screening knowledge tool: • women's knowledge about cervical cancer/screening (six items) • socio-demographic factors • cervical screening history	(Pitts and Clarke, 2002; CSSU, 2005) (CSSU, 2005) (Christie, Gamble and Creedy, 2005; CSSU, 2005)
How many Queensland women have heard of HPV, where did they hear about it and does this differ by socio-demographic factors, cervical screening history cervical cancer/screening knowledge?	• heard of HPV • socio-demographic factors • cervical screening history • cervical cancer/screening knowledge	(Pitts and Clarke, 2002)
What do Queensland women know about HPV and does this differ by socio-demographic factors, cervical screening history, cervical cancer/screening knowledge, awareness and attitudes?	• HPV true/false knowledge scale • 8 items re HPV • socio-demographic factors • cervical screening history • cervical cancer/screening knowledge • HPV vaccine awareness • General vaccine attitude scale • HPV vaccine attitude scale	(Kahn et al., 2003) (Pitts et al., 2007)
How many Queensland women have heard of HPV vaccine, where did they hear about it and does this differ by socio-demographic factors, cervical screening history cervical cancer/screening knowledge or awareness?	• heard of HPV vaccine • where heard about HPV vaccine • socio-demographic factors • cervical screening history • cervical cancer/screening knowledge • HPV awareness	(Pitts and Clarke, 2002)
What are Queensland women's attitudes towards HPV vaccination and does this differ by socio-demographic factors, cervical screening history cervical cancer/screening knowledge, awareness or attitudes?	• 6 item scale attitudinal scale • socio-demographic factors • cervical screening history • cervical cancer/screening knowledge • HPV awareness • HPV vaccine awareness • General vaccine attitudes	(Pitts et al., 2007)

An additional two items developed for the tool, were unintentionally omitted prior to the survey being conducted due to an administrative error.

- One item was added "The HPV vaccine works best when it is given before a young woman becomes sexually active" to explore if women were aware this was the reason the vaccine is targeted at 12 to 13 year old girls.

- As the majority of women in the study were not eligible to receive the publicly funded vaccine, due to age, questions were also modified to assess women's acceptability of the vaccine within the context of providing consent for a child. This was framed as a hypothetical question: "If I had a 12 year old daughter...." so all women were eligible respondents.
- The two items omitted accidently were "The HPV vaccine will prevent a high number of women from developing cervical cancer" and "Pap smears are not necessary if a woman has been vaccinated against HPV". To overcome this omission, these aspects of HPV vaccination were explored in Phase 2 of the study.

Women participating in the survey completed all screening knowledge and vaccination attitude items. Only women who responded they had heard of HPV were asked to respond to HPV knowledge items.

Women were asked about their attitudes towards vaccination in general before completing the HPV vaccination scale to determine if any resulting differences in attitudes were specific to the HPV vaccine. The following information was read out to participants prior to the HPV vaccination items being asked to ensure all women participating in the study could answer the HPV vaccination attitude questions, irrespective of whether they had previously heard of the vaccine or not: *"A vaccine has been developed against two types of the virus, HPV or human papillomavirus that cause up to 70% of cervical cancer. This free cervical cancer vaccine is primarily targeted at girls aged 12 to 13 years of age who are attending school".* This statement also provided clarity for respondents that the HPV vaccine and cervical cancer vaccine were one and the same.

The resulting Cervical Cancer/Screening and HPV Knowledge Tools and Vaccination Attitudes Scales are outlined in Appendix H. Demographic information and cervical screening history questions were adopted from previous Queensland CATI surveys conducted by the QCSP.

4.3.1 Validity of Survey Instruments

Content validity

Content validity is concerned with the sampling adequacy of the content area being measured and assesses how representative the questions on the test are of all

the questions that might be asked about the topic (Polit and Hungler, 1991). Content validity of the instruments used in this survey was determined by two methods recommended in the literature, a) using questions and variables on similar topics that have been used in other studies, following a review of the literature and, b) through subject matter expert judgment (Cheng, 2009; Aday and Cornelius, 2006). As described in Table 4.1, the questions used to measure cervical cancer/screening and HPV knowledge and the vaccination attitude scales were derived from previous studies with minor modifications.

Content validity was also assessed during the development of the questionnaire. Two experts were asked to review the items included in the knowledge instruments and provide validation of the items and responses used in these tools. The knowledge items were confirmed as accurate by these two experts who were:

- Dr Ian Hammond, Gynaecologist/Oncologist and Chairperson of the NCSP Review Committee for the National Health and Medical Research Council Guidelines for the Management of Women with Screen-detected Abnormalities Committee and the NCSP Renewal, and,
- Dr Caroline Harvey, Medical Director, Family Planning Queensland and Chairperson of the QCSP Quality Management Committee.

The instruments used in the CATI survey had not been validated in any of the original studies from which they were sourced and validation of these instruments was outside the scope of this study and is discussed further in the limitations section of this thesis (Section 9.3).

4.4 PROCEDURE AND TIMELINE

The CATI survey was conducted by an independent marketing agency, I-View Pty Ltd, engaged by Queensland Health.

Survey preparation

The Print Media and HPV Questionnaire (CATI survey) was developed by the researcher in collaboration with Ms Margaret Bright, an epidemiologist employed by Queensland Health. The component of the CATI survey designed to address the questions in this study was developed solely by the researcher.

As the CATI survey was developed for two specific purposes, two Queensland Health staff with extensive expertise in the design of CATI surveys, Ms Margaret Bright and Dr Gayle Pollard then reviewed the content and flow of the instrument. The ordering of questions was modified to optimise women's responses and provide a logical progression through the survey. Once this was finalised, briefings were held with staff from I-View Pty Ltd to specify the requirements for data collection who engaged an interview team to conduct telephone interviews and the following assurances were given:

- a dedicated project and supervisory team were allocated to the project
- due to the sensitive nature of the topic, only female interviewers with a good track record of performance were engaged for the survey
- all interviewers participated in a compulsory training, which encompassed six hours of theory, two hours (or more) of practical interviewing (live but not with a real client) and a two hour debriefing session following practice interviewing.

The content of the training program included:

- background to the study including relevant terminology
- an overview of the questionnaire structure and purpose of each section so that interviewers gained confidence, spontaneity and familiarity with all survey materials
- question by question coverage with techniques for probing as relevant
- key code frames
- participation maximisation techniques including correct use of survey introduction and how to handle difficult questions to ensure interviewers were able to respond with knowledge and conviction regarding the survey purpose whilst ensuring sensitivity to the needs of respondents
- call procedures and sample management issues
- protocols for telephone interviewing
- query resolution and problem escalation procedures

- role play and practice surveys (I-View Pty Ltd, 2008).

To ensure high quality of the interviews, interviewers were monitored for their first 10 real interviews. In these interviews, the supervisor guided or advised the interviewer without the respondent being aware of the conversation. The overall performance of each interviewer was also monitored during the telephone surveys and included daily monitoring by the project supervisor on the following:

- refusal rates
- probing techniques
- correct use of "other specify" codes
- incidence of use of "refusal" and "don't know" codes at the question level
- adherence to training guidelines and survey procedures
- comprehensiveness of call history notations (I-View Pty Ltd, 2008).

In addition, observation by remote listening device and validations through respondent re-contact and/or using remote listening equipment was conducted to validate 10% of the overall proportion of any interviewers' workload (I-View Pty Ltd, 2008).

These quality measures were reported to be higher than the standards set by Interviewer Quality Control Australia (IQCA) and interviewer training was also reported as beyond the guidelines set by the IQCA and the Australian Standard AS4752 (I-View Pty Ltd, 2008). In addition, I-View adhered to the Privacy Principles as per the Federal Government's Privacy Act and was accredited as meeting industry standards including the AS4752 and Australian Market and Social Research Society.

The questionnaire was pilot tested by the CATI facility to test the content, flow and average completion time. Thirty two surveys were conducted to pilot the instrument and there were no issues identified. It was estimated during the pilot study that the average length of time to complete the survey was between 15 and 20 minutes.

Call Routine

The first attempt to contact women was made between 5pm and 8pm weekday evenings and between 10am and 5pm on weekends. If this time was not convenient, a suitable time to call back was agreed. Set protocols were in place for the following outcomes:

- no answer or answering machines – delay two hours before re-issued to interviewers
- at start of a new shift, no-answers from previous evening were randomly scattered over the 3.5 hour period to avoid the majority of them being allocated early in the shift
- engaged numbers were delayed 15 minutes before re-issuing. - if engaged three times in a row, the number was not re-issued until one hour had passed
- call back appointments were issued to the appointment making interviewer no more than 5 minutes before they became due or to other interviewers one minute after they became due
- pre-dialled numbers were prioritised over unattempted numbers as follows:

1. 'hard' appointments – time scheduled for return call
2. 'soft' appointments – non-specific time made for return call or another household member suggested time to call when required person would be home
3. engaged
4. no-answer/machine
5. numbers not yet attempted (I-View Pty Ltd, 2008).

Timeline

The CATI survey was conducted between June 22 and June 29 2008 to meet timeframes relevant to the QCSP Social Marketing Campaign. The campaign was due to be aired again in July 2008 and it was important to gather data to inform a mid-term evaluation of the campaign prior to the next round of advertising.

4.5 QUANTITATIVE DATA ANALYSIS

Phase 1 was analysed first and used formatively to guide and inform phase 2 of the study.

4.5.1 Data Coding and Consistency Checking

I-View Pty Ltd provided raw data to Queensland Health. The coding framework was provided to the CATI facility with the original survey. This data was provided with some back coding of 'other - specifies', which were assessed by the Coding Manager. Additional codes were added to the existing code framework following approval by the Queensland Health team, including the researcher, for questions where multiple responses of a similar nature were provided by women that did not fit within the existing codes. The CATI facility developed the questionnaire to include built-in response validation and verification to prevent out of range or illogical responses, which was tested prior to fielding (I-View Pty Ltd, 2008).

In addition, the SPSS data file was cross checked by the I-View project team with the original data source (I-View Pty Ltd, 2008). A two-stage output editing process was undertaken by the CATI facility. Firstly a comprehensive computerised range and logic checks of the survey data was undertaken, which was followed by a detailed examination of survey frequencies to check the structure of survey data and the accuracy of any derived variables (I-View Pty Ltd, 2008).

Researcher Data Cleaning

Once the data file was received at Queensland Health, additional data cleaning was conducted. This included:

- range checks for all variables were conducted whereby none were found to contain out of range or invalid values
- recoding "other specifies' in variables where there were multiple responses that could be assigned to a specific category by the researcher who had content expertise
- variables were refined/constructed as outlined in Section 4.5.3
- additional consistency checks were undertaken and included:
    - refined/reconstructed variables were checked using cross-tabulations to assess for errors and were adjusted accordingly and rechecked.

4.5.2 Variable Definitions

The variables and how they were derived are described in this section as they relate to each research question. The research questions were previously outlined in Section 6.2.

Outcome (dependant variables)

Cervical cancer/screening knowledge was measured using a number of items that together formed the Cervical Cancer/Screening Knowledge Tool (Appendix H). The highest possible total score for the Cervical Cancer/Screening Knowledge Tool was 13 points (range 1–13). Awareness of HPV was measured by asking women if they had heard of HPV (yes/no/don't know).

HPV knowledge was measured using the HPV Knowledge Tool (Appendix H). The highest possible score for the tool was 12 (range 0–12). Awareness of the HPV vaccine was ascertained by asking women if they had heard of the HPV vaccine (yes/no/don't know) and where they had heard of it (multiple responses permissible).

Attitudes towards HPV vaccination was measured using the modified Victorian CATI survey attitude scale which contained six items (Pitts et al., 2007). This tool also contained eight items relating to vaccination in general, which were chosen as an outcome variable of interest to determine whether women's attitudes were consistent with vaccination in general or specific to the HPV vaccine. Attitude scores were compiled to form a score; the highest score was six (range 0–6) and eight (range 0–8) for HPV vaccination and general vaccination attitudes respectively, which were then converted to positive and negative attitudes.

Explanatory (Independent Variables)

Independent variables relevant to the study included socio-demographic factors, cervical screening history, awareness of HPV and the HPV vaccine, HPV vaccination status, cervical cancer/screening knowledge and general vaccination attitudes. These variables and their definitions are outlined in Appendix G.

Socio-demographic factors included age, location of residence, socioeconomic status, whether Australian born, Indigenous status, educational attainment, marital status, parity and smoking status. These variables were included as items of interest as they have been linked with lower participation in cervical screening or cervical cancer/screening knowledge in the literature (Section 2.2.1). Locality was measured

by collecting participants' postcode, which was then mapped to local statistical areas (SLAs) using concordance tables provided by the Epidemiology Team at the QCSP. These tables are used to determine SLAs for the purposes of reporting cervical screening participation by locality using Queensland PSR data. These SLAs were then mapped to the Australian Standard Geographical Classification (ASGC) as used by the Australian Bureau of Statistics (ABS) for the collection and dissemination of geographically classified statistics. The ASGC was chosen as this was the classification system used for PSR reporting purposes at the time the study was undertaken (ABS, 2006a).

Socio-economic status (SES) was also measured by collecting participants' postcode and was mapped to the SEIFA, index of socioeconomic disadvantage by the CATI facility and provided in deciles and quintiles of relative disadvantage (ABS, 2006b). SEIFA measures relative advantage and disadvantage at an area level, not at an individual level and depends on the socio-economic conditions of a community or neighbourhood as a whole, such as indicators of income, education or employment and may include characteristics of the area itself, such as a lack of public resources, transport infrastructure or high levels of pollution (ABS, 2006c).

Employment status and income were collected in the "Print Media and HPV Questionnaire" but were not used as markers of SES given women were assigned to SEIFA categories by residence as individual women's SES was less relevant to this study than community data given the results are to inform population screening policy. Educational attainment was ascertained by measuring three items, the highest level of schooling, if further qualifications were attained and what these were.

Cervical screening history included cervical screening status and a history of having experienced an abnormal Pap smear. Participant's cervical screening status was determined by looking at the usual time intervals women reported having Pap smears in combination with when they reported having their last Pap smear. Underscreened women were defined as those who screened less frequently than the recommended screening interval and for the purposes of this study were defined as women who had not had a Pap smear for more than three years, regular screeners had a Pap smear every two years and overscreeners reported having Pap smears more frequently than every two years. These variables were of interest to determine if

screening status or a history of an abnormal Pap smear were linked to knowledge and attiudes.

Awareness of HPV and awareness of the HPV vaccine were used as independent or dependent variables according to the research question of interest as was cervical cancer/screening knowledge. HPV knowledge was not used as an independent variable as it was made redundant by HPV awareness given women who had not heard of HPV did not complete it. Finally, general vaccination attitudes were included as an independent variable in the analysis of HPV vaccination attitudes.

4.5.3 Variable Derivation

A number of continuous variables were converted to categorical variables and some categorical variables were collapsed into either dichotomous variables or into smaller groups. The rationale for these modifications is described in this section and provided in summary in Appendix I.

Age was collected as a continuous variable and converted into a categorical variable of 10 year age groups to enable meaningful comparisons between age groups and consistency with groupings used for reporting cervical screening participation rates. A few respondents did not respond to this question and were asked by the interviewers for their date of birth. Their age was calculated by subtracting this date from the date the survey was conducted.

Locality was originally classified into five categories; however to avoid violation of the assumption of expected frequencies for the Chi square test during bivariate analyses and to maximise power in multivariable analysis, the remote, very remote locality categories were combined with the outer regional category. Socioeconomic status quintiles of most socioeconomic disadvantage were used without any changes to the coding provided from the CATI facility.

'Don't know' and 'refused to answer' were possible categories in the remaining socio-demographic, screening history and awareness questions. These were infrequent responses and were combined with 'no' responses. Only one person answered 'don't know' when asked about educational attainment and was excluded from the analysis, as it was not considered appropriate to assume the educational

status of this respondent and the sample size was large enough that it would have no impact on power in the analysis.

Educational status was measured by combining three variables into one, grouped to form the categories, 'less than year 10', 'years 10 to 12' schooling, 'certificate or diploma' and 'bachelor degree or higher'. Respondents who indicated they had not completed a higher qualification were categorised by their level of schooling whilst those who indicated they had, were categorised by their highest qualification completed. Marital status was collapsed into four categories – never married; married; defacto; separated, divorced and widowed to maximise power in the analysis due to small numbers in the separated, divorced and widowed categories.

Cervical screening status was derived by combining the variables, usual time between Pap smears and time since last Pap smear. These categories were not modified prior to combining into the one variable, although some women were assigned to an 'other' category. This category was used for women who indicated they had never had a Pap smear as they did not answer this question in the survey; had only ever had one test or were too young to have been eligible for further screening according to the NCSP policy or did not screen regularly but had had a Pap smear in the previous two years. Women's age was also taken into account in the development of this variable. Women who were over 23 years of age who reported they had only ever had one Pap smear or did not screen regularly were assigned to the category 'underscreened'.

The categories for smoking status were reclassified from categories, 'I smoke daily', 'I smoke occasionally,' 'I don't smoke now but I used to', 'I've tried it a few times but I never smoked regularly' or 'I've never smoked' to a dichotomous variable of current smoking status in which the first two categories were classified as 'yes' and all other categories 'no'.

Cervical cancer/screening knowledge scores were derived by allocating a score of '1' to the correct answer in each item about the purpose, recommendations and meaning of an abnormal result and combining this with the number of correct responses in the risk factor item. Incorrect answers and responses of 'don't know' scored '0' (Appendix H). Study participants' cervical cancer/screening knowledge scores were converted into a dichotomous categorical variable of knowledge levels using above and below average (mean) knowledge scores.

HPV true/false knowledge items were converted to a summary knowledge score by allocating correct answers a score of '1'. HPV knowledge scores were also converted into a dichotomous categorical variable of knowledge levels using above and below average (mean) knowledge scores.

Table 4.2. Possible Confounders of the Relationship between Dependent and Independent Variables of Interest

Independent variable	Possible confounder
Age	Education, marital status, parity, smoking status, screening status, history of previous abnormalities
Locality	Screening status
Socio-economic status	Education, marital status, parity, smoking status, screening status
Australian born	Education, marital status, parity, screening status
Educational attainment	Age, parity
Marital status	Age, parity
Parity	Age, marital status
Smoking status	Age, education, marital status, parity
Screening status	Age, geographic location, SES
History of previous abnormalities	Age, screening status, smoking status
Cervical cancer/screening knowledge	Age, screening status, country of birth, history of previous abnormalities
HPV awareness	Age, screening status, country of birth, history of previous abnormalities
HPV knowledge	Age, country of birth
HPV vaccination awareness	Age, screening status, country of birth,
General vaccination attitudes	Age, screening status, country of birth
HPV vaccination attitudes	Age, country of birth

An overall score for vaccination attitudes was ascertained by allocating a score of '1' to positive scores to vaccination statements whilst negative statements scored '0' (Appendix H). Neutral, 'don't know' and 'refused' responses scored '0' which is consistent with the method used by Pitts et al (2007). Scores were converted into a dichotomous categorical variable, namely positive and negative attitudes, with negative attitudes representing all responses that were not positive including uncertainty. Positive scores were those above three (central score of the scale) and negative scores were three and below.

Knowledge and attitude scores were converted into dichotomous categorical variables - below and above average knowledge levels and positive and negative

attitudes as these outcomes were deemed to be of greater clinical relevance for the purposes of this study. Identifying groups of women with above average and below average knowledge or those with postive and negative attitudes was considered more meaningful within the context of the researcher's area of practice as a public health practitioner than measuring these outcomes continously.

The conversion of attitude scores to positive and negative attitudes is also consistent with the method used by Pitts et al (2007) and therefore enabled comparisons to be made between relevant items in the two studies.

Multiple checks using cross-tabulations were undertaken following the groupings of variables to ensure the validity of the recoding and transformation of variables.

4.5.4 Confounding Variables

Confounding occurs when a relationship between a dependent and an independent variable occurs in whole or in part due to a third factor that is associated with both variables (Webb, Bain and Pirozzo, 2005). The potential for confounding of variables described in the explanatory variables section, such as age and education, marital status, parity and screening history, have been identified in the literature and are summarised in Table 4.2. Multivariable modelling was used to adjust for potential confounding of the relationships between independent and dependent variables.

4.6 STATISTICAL METHODS

Analysis of data collected from the CATI survey was performed using the Statistical Package for the Social Sciences (SPSS) Version 16.

4.6.1 Representativeness

Representativeness of the sample was considered by comparing participant characteristics for age, Australian-born, marital status, parity, highest level of schooling and post school qualifications with the 2006 Census of Population and Housing (ABS, 2006). Other characteristics, such as locality, SES, Indigenous status and smoking status, were compared with the Queensland Health Omnibus Survey data (Queensland Health, 2008). The marital status of women in the sample could not be directly compared to the Queensland population due to differences in the

categorisation of marital status between the two groups, specifically defacto relationships.

Data was received from the CATI facility unweighted; therefore weighting was applied to take into account the oversampling by socio-economic disadvantage and the quotas set for age. The raw data was adjusted to reflect the socio-economic and age profile of the 'benchmark population', namely, the Estimated Residential Population for Queensland 2006 based on results from the 2006 Census of Population and Housing. The weighting variable was provided to the researcher by the Queensland Health Epidemiology Team as this had also been applied to the QCSP Social Marketing Campaign component of the CATI survey. Application of the weighting variable resulted in a decrease of sample size from 1002 to 999.

Some variables, such as Indigenous (yes = 26; 3.2%) and HPV vaccination status (yes = 112; 13%), were excluded from bivariate and multivariate analysis due to the small numbers in these categories which would impact on the reliability of results due to lack of power.

As HPV knowledge was made redundant by HPV awareness as an independent variable, that is, only women who were aware of HPV answered the knowledge items, these variables were assessed separately in bivariate and multivariate analysis with cervical cancer/screening knowledge, HPV vaccination awareness, general vaccination and HPV vaccination attitudes.

4.6.2 Testing Assumptions for Tests and Models

Appropriate assumption testing was applied prior to conducting bivariate and multivariable tests and models.

When continuous scores were described for knowledge and attitude scores, the assumption of normality was established before means and standard deviations were derived. Normality was established using the following criteria:

- means within 10% of median
- minimum and maximum are approximated by the mean $\pm$ 3sd
- skewness and kurtosis both within $\pm$ 3
- a roughly symmetrical histogram (Battistutta, 2010a).

Assumptions behind bivariate and multivariable test/models were also checked. Assumptions for the appropriate use of the Chi-square test were tested:

- all expected cell counts were greater than five or categories were collapsed to meet this assumption as necessary (for example, locality)
- the sample was randomly selected so there was independence of observations.

Each participant came from a randomly sampled household across Queensland. It was therefore unlikely that selected households would influence each other with respect to cervical cancer/screening knowledge, HPV knowledge, awareness of HPV and the HPV vaccine and attitudes towards HPV vaccination. All categories were mutually exclusive with the exception of HPV awareness and HPV knowledge, which were not included together in any bivariate analysis or models.

Prior to multivariable modelling testing for multicollinearity was undertaken to ensure none of the independent variables were measuring the same concept as this makes it difficult to assess the individual performance of an indicator (Field, 2009). A strong correlation between two or more variables in the model was not anticipated, nor present when assessed. To prevent violation of the assumption of multicollinearity, known or suspected correlated independent variables in the model were tested by obtaining collinearity diagnostics for each model and obtaining tolerance and variance inflation factor (VIF) statistics as described by Field (2009). There were no tolerance values less than 0.1, nor VIF values greater than 10 found in any models (Appendix J). Eigenvalues of the scaled, uncentred cross-products matrix were also considered acceptable with no large values identified and so all variables were retained in the models.

4.6.3 Criteria Used for Reporting Significant Associations

Significance testing was undertaken and results were determined to be statistically significant different at the pre-defined 5% significance level with a 95% confidence interval. Clinical significance was defined for differences between cervical cancer/screening knowledge scores, HPV knowledge scores and vaccination attitude scores based on the findings of previous studies (Hancock et al., 1996; Pitts and Clarke, 2002).

As outlined in Section 4.2, sample sizes were originally calculated based on differences in mean knowledge scores; however it was decided to convert these scores into dichotomous categorical variables - below and above average knowledge levels and positive and negative attitudes as these outcomes were deemed to be of greater clinical relevance for the purposes of this study, and the planning of changes relevant to the QCSP.

A difference of greater than 10% in the proportions of women in one group (e.g. younger women) achieving above average cervical cancer/screening and HPV knowledge levels and attitudes towards the HPV vaccine when stratified by independent variables was determined to be clinically significant. These parameters were also applied to HPV and HPV vaccination awareness.

4.6.4 Analysis of Correlates of Independent Variables

Bivariate Analysis

Bivariate analysis was undertaken to explore the relationships between knowledge and attitude scores and participant characteristics. This was done using crosstabulation of frequencies and percentages and the Likelihood chi-square test for dichotomous categorical independent variables. Bivariate results are provided in Appendix K.

Multivariable Analysis

As the study was non-experimental in design, a multivariable modelling approach was chosen to permit consideration of a range of factors already established to be associated with differences in knowledge and attitudes about cervical cancer/screening, HPV and the HPV vaccine. As the main outcome variables were dichotomous categorical variables and all independent variables were also categorical variables, binary logistic regression was chosen for multivariable modelling.

This assisted with determining significant relationships between variables and in identifying confounding variables. Modelling was conducted to control for confounding between variables that have been explored in multiple studies about cervical cancer/screening knowledge, HPV knowledge and attitudes towards the HPV vaccine as previously identified (Sections 2.4.1, 2.4.2 and 2.5.3).

Referent groups were chosen based on those factors that have been linked with increased risk for cervical cancer or decreased participation in cervical screening as identified in the literature (Table 4.3).

Independent variables were entered into each model by forced entry as this was an exploratory study (Field, 2009). In all models, non-significant variables were then removed. Each level of influence within the model was assessed using a pseudo-R^2 statistic (Nagelkerke's) to determine the relative contribution of each independent variable within the model.

The effect size of some variables changed from the crude to the adjusted relationship. Suspected confounding factors were removed from the final model one at a time and then returned. A shift in the odds ratio of greater than 10% was assumed to explain the shift in effect size following adjustment.

Table 4.3. Referent Variables Chosen for Multivariable Models

Variable	Referent Category
Age	20–29 years
Locality	outer regional, remote, very remote
Socioeconomic status	quintile 1
Australian born	no
Educational attainment	year 10 or below
Marital status	never married
Had children	no
Smoking status	yes
Screening status	underscreened
Abnormal Pap history	yes
Cervical cancer/screening knowledge	below average
HPV awareness	no
HPV vaccination awareness	no
General vaccination attitudes	negative

The best goodness of fit in all models as determined by the R^2 (Nagelkerke's) was highest when all potential confounding variables were included. Each final model therefore included all variables.

Interactions between screening status and age, screening status and abnormal Pap smear and age and abnormal Pap smear were tested one at a time in the cervical cancer/screening knowledge model to assess for effect modification; however insufficient power in the model was reflected with large standard errors and wide confidence intervals and these interactions are not reported and were not tested in subsequent models.

The key findings relevant to the aims of Phase 1 as described in Section 4.1 are described in the next chapter, 'What Queensland Women Know about Cervical Cancer/Screening, HPV and the HPV Vaccine'.

Chapter 5: What Queensland Women Know about Cervical Cancer/Screening, HPV and the HPV Vaccine

This chapter describes the research findings from Phase 1: the quantitative component of the study, a computer-assisted telephone interview (CATI) survey of 1002 Queensland women. The characteristics of women who participated in the survey are firstly described (Section 5.1), followed by women's cervical screening history in Section 5.2. The knowledge amongst participants in the survey about cervical cancer/screening (Section 5.3), awareness of human papillomavirus (HPV) (Section 5.4) and HPV knowledge (Section 5.5) is then outlined and the chapter concludes with Section 5.6, which describes women's awareness and attitudes towards HPV vaccination.

The secondary research questions and hypotheses to be tested in Phase 1 of the study are described in Section 4.1.

5.1 SAMPLE CHARACTERISTICS AND REPRESENTATIVENESS

5.1.1 Response Rate

The response rate achieved for the survey as defined by the CATI facility was 76.9%, which was calculated as follows: (interviews + non qualifiers) / (interviews + non qualifiers + refusals) where there were 1002 interviews, 2730 non qualifiers (no women in household aged 20–69 years + respondent had hysterectomy) and 1123 refusals (I-View Pty Ltd, 2008). If non-qualifiers are excluded from these calculations the response rate calculated as follows: interviews / (interviews + refusals) was 47.2%.

5.1.2 Socio-demographic Characteristics of Study Participants

The mean unweighted age of study participants was 42.6 years (SD 13.03) with the majority of women aged between 30 and 49 years (47%). Most women lived in major cities (40%) and lived in the area of most socio-economic disadvantage (26%). Study participants were also more likely to be Australian born (82%) and non-Indigenous Australians (97%), be married (62%) and have had children (80%). The majority had attended school beyond Year 10 (63%) and had completed a post school qualification (64%), which was most commonly identified as a diploma or certificate and report they were not current smokers (79%).

Table 5.1. Characteristics in a Community Sample of 1002 Women, Queensland, 2008

	UNWEIGHTED		WEIGHTED		
Socio-demographic Characteristics	**N = 1002**	**%**	**N=999**	**%**	**% (QLD)**
Age (10 year age groups)					
20–29	197	19.7	249	24.9	20.6[1]
30–39	238	23.8	260	26.0	22.9
40–49	231	23.1	230	23.0	23.2
50–59	212	21.2	164	16.5	20.1
60–69	124	12.4	96	9.6	13.3
Locality					
remote,very remote	33	3.3	30	3.0	2.4[2]
outer regional	237	23.7	223	22.4	17.4
inner regional	326	32.5	296	29.7	26.7
major cities	406	40.5	450	45.0	53.5
Socio-economic Status					
quintile 1 (most disadv)	257	25.6	176	17.6	12.5[2]
quintile 2	234	23.4	184	18.4	21.5
quintile 3	120	12.0	152	15.2	26.9
quintile 4	159	15.9	194	19.4	23.0
quintile 5 (least disadv)	232	23.2	294	29.4	16.1
Country of Birth					
United Kingdom (UK)	52	5.2	48	4.8	6.4[1]
New Zealand (NZ) & Oceania	46	4.6	46	4.6	5.2
Other	84	8.4	91	9.1	17.8
Australia	820	81.8	814	81.5	70.6
Aboriginal or Torres Strait Islander					
yes	26	3.2	26	3.2	2.9[2a]
no	793	96.7	787	96.7	97.1
refused to answer	1	0.1	1	0.1	–
Highest level completed at school					
never attended	4	0.4	3	0.3	0.5
less than year 10	75	7.5	59	5.9	13.8
year 10 or equiv	292	29.1	261	26.1	29.0
greater than year 10	627	62.6	673	67.4	46.8
don't know/not stated	4	0.4	4	0.4	10.0
Post school qualifications [b]					
yes	637	63.6	653	65.3	44.5[1]
no	365	36.4	346	34.6	54.8
Post school qualifications - stated					
certificate or diploma	415	65.1	402	61.5	34.1[1]
bachelor degree or higher	216	33.9	245	37.5	10.4
don't know/ not stated	6	0.9	6	0.9	–
Educational attainment					
year 10 or below	201	20.1	175	17.5	
year 11or 12	165	16.5	173	17.3	
certificate or diploma	417	41.7	404	40.5	
bachelor degree or higher	217	21.7	246	24.7	
Marital status [c]					
never married	116	11.6	141	14.1	33.3[1;d]
married	625	62.4	595	59.5	55.1
defacto	146	14.6	167	16.7	11.6
separated/divorced/widowed	115	11.5	97	9.7	–
Children					
no	201	20.1	242	24.2	25.8[1]
yes	801	79.9	757	75.8	68.5
Smoking Status					
current smoker	210	21.0	206	20.6	21.8[3]
past smoker	241	24.1	236	23.6	26.4
never smoked regularly	550	54.9	556	55.6	51.8
refused to answer	1	0.1	1	0.1	0.0

Table 5.1 continued

[1.] Source: Australian Census 2006 (ABS, 2006a)
[2.] Source: Queensland Health Info Bank (Queensland Health, 2011)
[3] Source: Queensland Health Omnibus Survey (Queensland Health, 2008)
[a] Age range in source database - 20 to 64 years
[b] Age range 15 years and over
[c] Age range in source database – 20 to 74 years
[d] Category is' not married' and includes separated/widowed/divorced

Characteristics of study participants are outlined in Table 5.1 and have been presented unweighted and weighted and, where available, have been compared to women in the Queensland population as a whole.

5.1.3 Representativeness

When compared to the Queensland population (Table 5.1), the sample prior to weighting was similar by age across all 10 year age categories, Indigenous status and smoking status. As designed, the sample was under-representative of those living in major cities and quintiles 3 and 4 and over-representative of women living in inner and outer regional and remote areas and quintile 1. There were a higher number of women in the sample born in Australia (82%) compared to the Queensland population (71%) and a higher proportion of women in the sample who had children (80%). Study participants were more likely to report they had attended school beyond Year 10 and completed post school qualifications.

The marital status of women in the sample could not be directly compared to the Queensland population due to differences in the categorisation of marital status between the two groups, specifically in relation to the categories never married and not married. Due to the differences between the sample and the Queensland population, the findings are not fully generalisable to the Queensland population with respect to location, socio-economic status (SES), country of birth, education, marital status and parity.

When the weighting variable was applied, the mean age of participants was 40.1 years (SD 12.92) and the sample was more representative by locality, SES, having children, similar by Indigenous status, country of birth, post school qualifications and smoking and slightly less representative by education and age, the latter which was an effect of the weighting for SES when combined with the weight applied for age. All results presented in the remainder of this chapter are weighted for age and SES.

5.2 CERVICAL SCREENING HISTORY

To ascertain women's cervical screening history, study participants were asked about their previous experience of screening, including how regularly they had Pap smears, how many previous Pap smears they had, when they last had a Pap smear and if they had ever had an abnormal Pap smear in the past. The following section describes women's screening history and describes factors associated with women's screening status or history of a previous abnormal Pap smear.

5.2.1 Personal Cervical Screening History

The majority of study participants (96%) had had at least one Pap smear prior to completing the survey with two respondents indicating they did not know about the test. Most women who had never had a Pap smear (n=36) were less than 30 years of age and the majority of these women, when this category was explored further, were aged less than 25 years (n=28) as highlighted in Figure 5.1. Eighty-four percent of women said they had a Pap smear every two years or less, with most women (77%) reporting their last Pap smear was within the previous two years. Just over three percent of respondents reported they had not had a Pap smear for five or more years (Table 5.2). When compared with Queensland Pap Smear Register (PSR) data, the proportion of women in this study who reported they had had a Pap smear within the two year reporting period of 2007/08 was much higher. The state-wide participation rate for the target age group of women aged 20 to 69 years in Queensland was 57.9% in 2007/08 compared to 84% of women in this study (QCSP, 2012). This suggests women who consented to participate in this study were either more likely to have regular Pap smears than women in the general population, or had under-estimated the length of time that had lapsed since their last Pap smear. The implications of screening status on the findings of this study are discussed further in Section 9.3.2.

Seventy-one percent reported the usual time between their Pap smears was greater than one and less than two years, whilst only two percent reported they did not have regular Pap smears (Table 5.2). Forty percent of women had had more than 10 Pap smears in their lifetime. Only 25 women reported only ever having had one test when asked about how regularly they had Pap smears whereas 53 women reported they had only ever had one test when asked how many times they had had a Pap smear. Further exploration revealed that this discrepancy was due to 23 women who responded their usual time between Pap smears was

every one or two years, were young women who had previously only had one test, and suggests they were reporting their intended screening behaviour for the future.

Table 5.2. Cervical Screening History in a Community Sample of 1002 [a] Women, Queensland, 2008

Screening history	N = 999[a]	%
Ever had a Pap smear		
yes	961	96.2
no	36	3.6
not sure	1	0.1
don't know about this test	2	0.2
Screening History		
never had a Pap smear	36	3.6
only ever had 1 test	25	2.5
screened every 2 years or less	838	83.8
screened > 2 years or more	84	8.4
don't know/refused to answer	17	1.7
Last Pap smear [b]		
< 1 year ago	444	44.5
1 year to < 2 years ago	322	32.2
2 years to < 3 years ago	124	12.4
3 years to < 5 years ago	34	3.4
5 or more years ago	34	3.4
don't know	4	0.4
Usual time between Pap smears [b]		
1 year or less	156	16.3
> 1 year to 2 years	681	70.9
> 2 years to 3 years	37	3.8
4 years or more	24	2.5
only ever had 1 test	25	2.6
don't have a regular test/other	23	2.4
don't know/refused	14	1.5
Number of times had Pap smear [b]		
once	53	5.3
twice	57	5.8
3–5 times	176	17.7
6–10 times	246	24.6
11–20 times	269	26.9
more than 20 times	127	12.8
don't know / can't remember	31	3.1
refused to answer	2	0.2

[a] Weighted sample N = 999

[b] Excludes women who had never had a Pap smear; or reported don't know/not sure when asked "Have you ever had a Pap smear'.

5.2.2 Screening Status

Cervical screening status was derived by combining the variables, usual time between Pap smears and time since last Pap smear as outlined in Section 4.5.3. The majority of women (62%) reported they were regular screeners with 15% of participants classified as underscreeners, 18% as overscreeners and four percent classified in the 'other' category (Figure 5.2). The 41 women in the 'other' category included women who did not know when

they last had a Pap smear and/or how regularly they had them, young women who had only had one test and were not eligible for a repeat Pap smear as their last Pap smear was less than two years previously and women who did not test regularly but reported they had had a Pap smear in the previous two years.

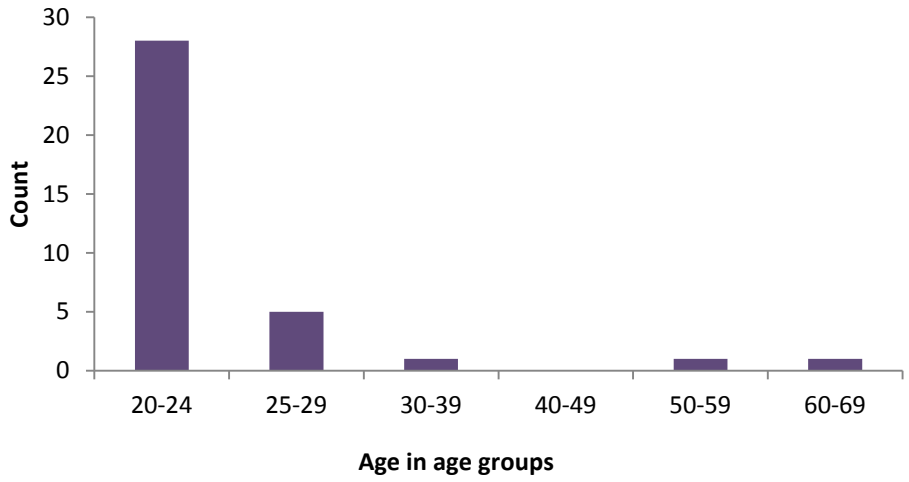

Figure 5.1. Study Participants who had never had a Pap Smear by Age Group (n=36)

Women in the 'other' category were excluded from further analysis as they did not represent a screening category per se. In addition, the number of women in this category was too small for meaningful analysis when screening status was stratified by other variables.

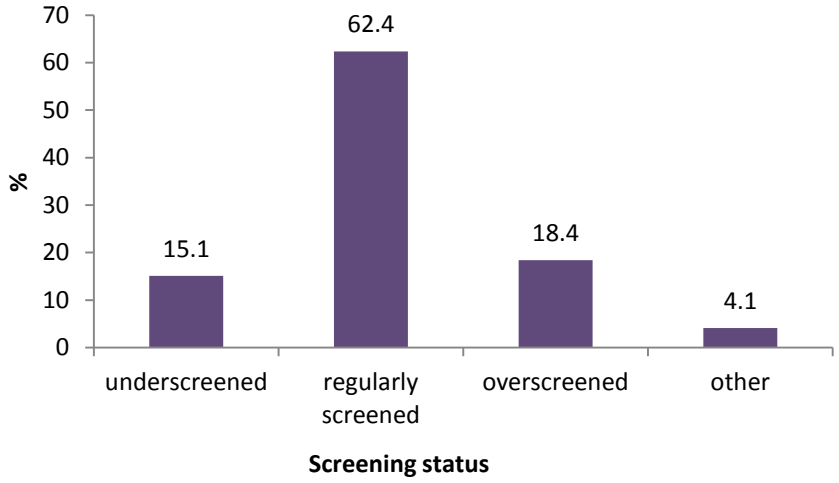

Figure 5.2. Study Participant's Screening Status (n=999)

As evident in Table 5.3, there were no statistically significant differences observed in screening status by age, locality, country of birth or educational attainment.

Table 5.3. Cervical Screening Status and Characteristics in a Community Sample of 1002[a] Women, Queensland, 2008

	Screening Status n=958[b]							
	underscreened		regularly screened		overscreened		X^{2} [c]	*P* [d]
	N (151)	% (15.7)	N (623)	% (65.1)	N (184)	% (19.2)		
Age							12.44	0.13
20–29	45	21.0	131	60.6	40	18.5		
30–39	40	15.5	168	65.0	51	19.5		
40–49	29	12.9	154	67.9	44	19.2		
50–59	22	13.8	102	62.2	39	24.1		
60–69	13	14.5	69	74.0	11	11.6		
Locality [e]							2.41	0.66
outer reg, rem, vremote [e]	39	15.5	170	68.2	41	16.3		
major cities	66	15.7	267	63.2	89	21.1		
inner regional	46	16.0	186	64.9	54	19.0		
Socio-economic status							15.27	0.05
quintile 1 (most disadv [e])	36	21.2	108	63.3	26	15.4		
quintile 2	24	13.8	124	70.2	28	16.0		
quintile 3	24	16.2	95	65.3	27	18.5		
quintile 4	25	13.4	132	69.6	32	17.0		
quintile 5 (least disadv)	41	14.9	164	59.5	70	25.5		
Australian born							1.36	0.51
no	31	18.6	107	64.0	29	17.4		
yes	120	15.1	516	65.3	155	19.6		
Educational attainment							7.09	0.31
year 10 or below	25	14.3	122	70.7	26	15.0		
year 11or 12	28	17.4	102	63.0	32	19.6		
cert or diploma	57	14.6	245	62.9	88	22.5		
Ba degree or higher [f]	41	17.6	153	65.7	39	16.7		
Marital status							34.67	<0.01
never married	37	31.4	58	49.6	22	18.9		
married	73	12.5	412	70.2	102	17.3		
defacto	19	12.2	99	62.7	40	25.1		
sep/div/wid [f]	21	22.0	55	56.6	21	21.4		
Had children							9.56	0.01
no	46	21.6	120	56.8	46	21.6		
yes	105	14.1	504	67.4	139	18.5		
Smoking status							11.41	<0.01
yes	46	23.4	111	56.2	40	20.5		
no	105	13.7	513	67.3	144	18.9		
Abnormal Pap history							88.85	<0.01
yes	22	7.4	163	55.7	108	36.9		
no	129	19.4	461	69.2	76	11.5		

[a] Weighted sample N = 958
[b] Excludes women from the 'other' screening status category
[c] Likelihood Ratio – Chi square
[d] *p* = significance at < 0.05
[e] outer regional, remote and very remote categories combined
[f] outer reg, rem, vremote = outer regional, remote and very remote; disadvant – disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

Significant differences by screening status were observed by SES, marital status, having had children, smoking status and a past history of an abnormal Pap smear. Underscreened women were more likely to be from areas of most socio-economic

disadvantage (Likelihood X^2 = 15.27, 8 df, p = 0.05), more likely to be never married (Likelihood X^2 = 34.67, 6 df, p <0.0001), less likely to have children (Likelihood X^2 = 9.56, 2 df, p = 0.008), more likely to be smokers (Likelihood X^2 = 11.41, 2 df, p = 0.003) and less likely to report a previous abnormal Pap smear result (Likelihood X^2 = 88.85, 2 df, p <0.0001).

5.2.3 History of Pap Smear Abnormalities

Almost 30% of respondents reported having had an abnormal Pap smear in the past. This represents abnormalities detected over the entire span of these women's screening history and as women were not asked to specify the abnormality, may also include benign or insignificant abnormalities including technically unsatisfactory smears, candida albicans (thrush) and atrophic smear results (Table 5.4).

Women participating in the study who reported having had an abnormal Pap smear in the past were significantly more likely to be aged 30 to 39 years, live in remote and very remote areas, reside in quintile 3, be born in Australia, have completed a certificate or diploma or less than year 10 at school, be in a defacto relationship, have children and report they were current smokers (Table 5.4).

5.3 CERVICAL CANCER/SCREENING KNOWLEDGE

To ascertain what Queensland women know about cervical cancer/screening and whether this differs by socio-demographic factors or cervical screening history, study participants were asked about National Cervical Screening Program (NCSP) screening policy recommendations, the purpose of the Pap smear, the meaning of results and and risk factors for cervical cancer.

5.3.1 Cervical Screening Knowledge

Women's knowledge of cervical cancer/screening varied with moderate to high knowledge levels observed in response to questions regarding the purpose, meaning of results and recommended frequency of Pap smears. However, knowledge about the age range of the eligible target population was limited. There were also high levels of uncertainty expressed about some risk factor items.

The majority of respondents (82%) correctly identified the purpose of the Pap smear was to detect abnormal cells. Nineteen percent of participants thought the Pap smear was a

treatment for cancer, seven percent incorrectly thought it could detect sexually transmitted infections, whilst less than one percent thought it was a test for HPV.

Table 5.4. Abnormal Pap Smear History and Characteristics in a Community Sample of 1002[a] Women, Queensland, 2008

	Abnormal Pap history					
	Yes		No [b]			
	N (293)	% (29.6)	N (706)	% (70.4)	X^{2} [c]	*P* [d]
Age in 10 yr groups					48.560	<0.0001
20–29	39	15.8	210	84.2		
30–39	101	38.6	160	61.4		
40–49	77	33.3	153	66.7		
50–59	60	36.5	104	63.5		
60–69	17	17.4	79	82.6		
Locality					4.05	0.26
remote,very remote	11	38.4	18	61.6		
outer regional	70	31.2	154	68.8		
inner regional	93	31.5	203	68.5		
major cities	118	26.3	331	73.7		
Socioeconomic status					2.95	0.57
quintile 1 (most disadv [e])	49	28.0	127	72.0		
quintile 2	57	30.8	127	69.2		
quintile 3	52	34.3	100	65.7		
quintile 4	56	28.8	138	71.2		
quintile 5 (least disadv)	79	27.0	214	73.0		
Australian born					2.82	0.09
no	45	24.3	140	75.7		
yes	248	30.5	566	69.5		
Educational attainment					9.02	0.03
Yr 10 or below	57	32.4	118	67.6		
Yr 11or 12	46	26.4	127	73.6		
cert or diploma [e]	134	33.1	270	66.9		
Ba degree or higher [e]	57	23.1	189	76.9		
Marital status					19.7	<0.0001
never married	21	15.1	120	84.9		
married	183	30.8	411	69.2		
defacto	59	35.1	108	64.9		
sep/div/wid [e]	30	30.8	67	69.2		
Had children					19.19	<0.0001
no	45	18.4	198	81.6		
yes	248	32.8	509	67.2		
Smoking status					3.86	0.05
yes	72	34.9	134	65.1		
no	221	27.9	572	72.1		

[a] Weighted sample N = 999
[b] Women who had never had a Pap smear included in 'no' category (n=36)
[c] Likelihood ratio - Chi square
[d] *p* = significance at p <0.05
[e] disadvant = disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

A number of women (n=43) were very general in their responses, for example, 'search for any issues' and 'making sure you're right' and these responses were assigned to the 'other' category. When asked what an abnormal Pap smear most commonly means, almost half the women sampled (49%) correctly identified an abnormal Pap smear as containing

abnormal or precancerous cells, 27% thought it most commonly meant that the woman had cancer and 11% did not know what an abnormal result meant (Table 5.5).

Table 5.5. Cervical Screening Knowledge in a Community Sample of 1002[a] Women, Queensland, 2008

Cervical Screening Knowledge Questions	N=999	%
What do you think a Pap smear is a test for? [b]		
A test to look for abnormal cells (correct response)	815	81.6
Treatment for cancer	189	18.9
A test for a sexually transmitted infection	74	7.4
Other	43	4.4
General women's health	14	1.4
HPV	7	0.7
Don't know	10	1.0
What do you think an abnormal Pap smear test most commonly means? [c]		
Abnormal, precancerous cells (correct answer)	494	49.4
Cancer	275	27.5
Something wrong / follow-up/further investigation/tests needed	178	17.9
Infection	78	7.8
Other	61	6.1
Don't know / no response	106	10.6
How often do you think a woman should have a Pap smear?		
Every year	212	21.2
Every 2 years (correct response)	724	72.4
Every 3–5 years	17	1.7
Some other time period	34	3.4
Don't know	13	1.3
When or at what age do you think it is recommended to start having Pap smears?		
Less than 18	75	7.5
18–20 (correct response)	163	16.3
21–25	44	4.4
>26	53	5.3
When they become sexually active	587	58.7
Other	30	3.0
Don't know/refused (n=2)	48	4.8
When do you think it is recommended women should stop having Pap smears?		
No specific time recommended	317	31.7
Never	235	23.5
70 years of age / over 70 years of age (correct response)	105	10.6
At menopause	69	6.9
When they are no longer sexually active	25	2.5
Following a hysterectomy	12	1.2
Other	45	4.5
Don't know	191	19.1

[a] Weighted sample N = 999
[b] Unprompted and multiple responses permissible – total responses 1153
[c] Unprompted and multiple responses permissible – total responses 1199

Responses assigned to the 'other' category included 'blockage and 'disease inside' and were too broad to include in a specific category.

The majority of women (72%), correctly identified the recommended screening interval as every two years, although one fifth responded the recommendation was yearly. Most women (59%), incorrectly believed sexual debut was the recommended time for women to start having Pap smears, with only 16% identifying the correct time of 18 to 20 years of age. Responses allocated to the 'other' category included 'after marriage', 'at puberty' and 'as soon as they have a baby'. Women were also unclear about when it was appropriate for cervical screening to cease with most women responding there was no recommendation (32%) or never (24%) (Table 5.5). Only 11% of respondents responded correctly that Pap smears could cease at 70 years of age and a further one percent were aware that women could cease having Pap smears after a hysterectomy. Other responses included 'when they are dying', 'when the doctor says so' and 'as long as they have a husband'.

5.3.2 Knowledge about Risk Factors for Cervical Cancer

Women's responses to questions about risk factors for cervical cancer are described in this section. When prompted, most women (74%), correctly identified HPV, not having regular Pap smears (73%) and smoking (61%) as risk factors for cervical cancer (Table 5.6).

Table 5.6. Knowledge of Risk Factors for Cervical Cancer in a Community Sample of 1002[a] Women, Queensland, 2008

Response to Whether Factor Increases a Woman's Risk of Cervical Cancer						
	Yes		No		Don't know	
	N	%	N	%	N	%
A family history of cervical cancer (no)	898	89.8	80	8.0	22	2.2
HPV (yes)	739	74.0	84	8.4	176	17.6
Not having regular Pap smears (yes)	733	73.3	244	24.4	23	2.3
Having lots of sexual partners (yes)	718	71.9	231	23.1	51	5.1
Smoking (yes)	609	60.9	279	27.9	111	11.1
Not using condoms (yes)	591	59.1	351	35.2	57	5.7
Having genital warts (no)	561	56.1	279	28.0	159	15.9
Poor hygiene (no)	521	52.2	395	39.5	83	8.3
Starting sex at a young age (yes)	490	49.0	413	41.3	97	9.7
Stress (no)	481	48.2	425	42.6	93	9.3
Taking the oral contraceptive pill (yes)	328	32.8	501	50.1	171	17.1
Having lots of sex (no)	281	28.1	607	60.8	111	11.1
Being overweight (no)	257	25.7	593	59.3	150	15.0
Having many pregnancies/children (yes)	167	16.7	726	72.6	107	10.7

[a] Weighted sample N = 999
(yes) indicates correct response

The majority of participants also correctly identified factors associated with sexual activity (and therefore the acquisition of HPV) including not using condoms (59%), having lots of sexual partners (72%) and starting sex at a young age (49%), although there were also moderate proportions of women (35%, 23% and 41%, respectively) who did not consider these risk factors (Table 5.6). Most women correctly identified that being overweight (59%) or having lots of sex (61%) were not identified risk factors for cervical cancer.

Almost 90% of participants incorrectly believed family history increased a woman's risk of cervical cancer with less than two percent unsure about this. Poor hygiene, stress and having genital warts were also incorrectly identified as risk factors by approximately half of the participants. Participants were also largely unaware that taking the oral contraceptive pill (50%) and having many pregnancies or children (73%) are factors that have been linked to increased risk of cervical cancer. There was considerable uncertainty expressed about the role of some risk factors. More than 17% of women indicated uncertainty about the role of HPV and the oral contraceptive pill and 10% of women or more did not know whether having genital warts, being overweight, smoking, having many pregnancies or children, having lots of sex or starting sex at a young age were important risk factors for cervical cancer (Figure 5.3).

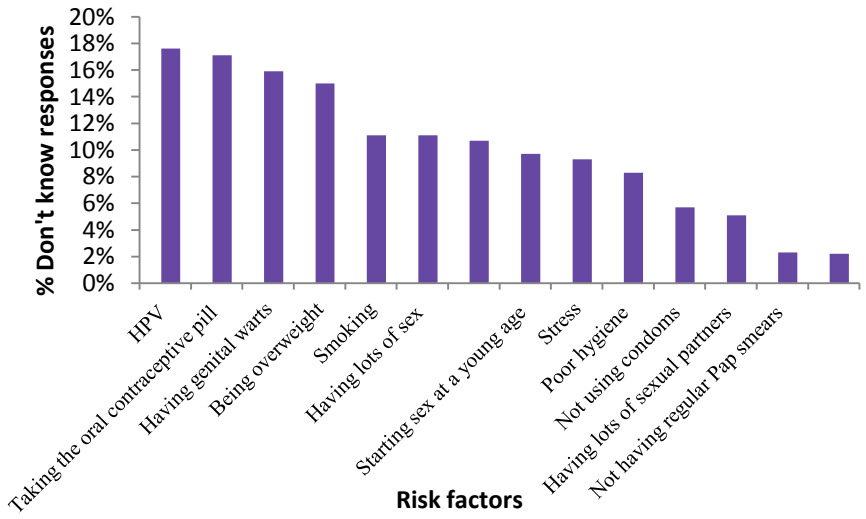

Figure 5.3. Uncertain Responses to Risk Factors for Cervical Cancer (n=999)

Women's responses to cervical cancer/screening knowledge items were scored, summarised and then converted into above and below average scores for bivariate and multivariable analysis as described in Section 4.5.3. The highest possible total score for cervical cancer/screening knowledge was 13 points. The average cervical cancer/screening

knowledge score of the women surveyed was 6.64 (SD = 2.11). Scores were normally distributed and the average knowledge score was similar to the central score of the scale. Two participants scored 12, the highest score obtained by participants on the knowledge scale, whilst one respondent answered all items incorrectly or with uncertainty and subsequently scored zero (Figure 5.4).

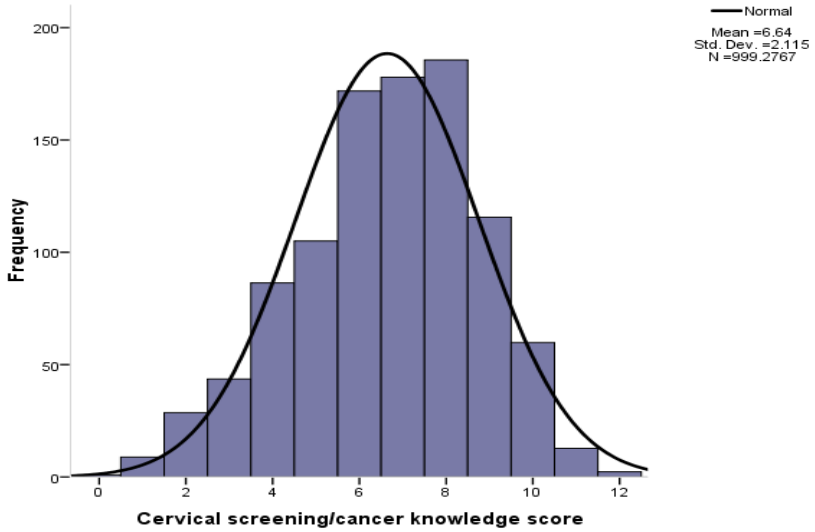

Figure 5.4 Histogram of Cervical Cancer/Screening Knowledge Scores (n=999)

When cervical cancer/screening knowledge was stratified by socio-demographic factors and cervical screening history, there was little variation observed through bivariate analysis by any factors except screening status (Appendix K). Multivariable analysis was undertaken as a number of independent variables in the bivariate analysis were potential confounders of each other in their relationships with cervical cancer/screening knowledge, such as age and screening status. Factors included in the final model explained only two percent (Nagelkerke's R Square = 0.025) of the variation in cervical cancer/screening knowledge levels. This reflects the small amount of variation in cervical cancer/screening knowledge in the sample and that there are other sources of variation in knowledge not captured in this study.

Following mutual adjustment for all variables in the model, the lack of associations observed in bivariate analysis were confirmed as there was limited impact on the significance of any factors in relation to cervical cancer/screening knowledge scores (Table 5.7).

Table 5.7. Multivariable Relationships between Women with Above Average Cervical Screening Knowledge and Demographic and Screening History Variables in a Community Sample of 1002[a] Women, Queensland, 2008

	Cervical Cancer/Screening Knowledge						
	No of women (999)	% above average (55.4)	Crude OR[b]	Adjusted[c] OR[c]	95% C.I.[d]		Sig[e]
SOCIODEMOGRAPHIC							
Age (10 year age groups)							
20–29	249	55.5	1.00	1.00	(referent)		0.95
30–39	260	55.4	1.00	0.91	0.60	1.37	
40–49	230	54.4	0.96	0.88	0.57	1.35	
50–59	164	55.0	0.98	0.86	0.54	1.39	
60–69	96	58.6	1.13	1.02	0.58	1.78	
Locality							
outer reg, rem, vremote [f]	252	56.3	1.00	1.00	(referent)		0.26
major cities	450	57.8	1.06	1.08	0.76	1.54	
inner reg [f]	297	51.2	0.82	0.82	0.58	1.16	
Socioeconomic status							
quintile 1 (most disadv [f])	176	57.0	1.00	1.00	(referent)		0.55
quintile 2	184	50.7	0.78	0.71	0.46	1.09	
quintile 3	152	56.4	0.98	0.93	0.59	1.48	
quintile 4	194	55.0	0.92	0.80	0.52	1.24	
quintile 5 (least disadv)	294	57.3	1.01	0.91	0.59	1.41	
Australian born							
no	185	57.1	1.00	1.00	(referent)		0.64
yes	814	55.1	0.92	0.92	0.65	1.31	
Educational attainment							
year 10 or below	175	54.3	1.00	1.00	(referent)		0.82
year 11or 12	173	56.2	1.08	1.07	0.67	1.69	
cert or diploma[f]	404	56.1	1.08	1.07	0.73	1.57	
Ba degree or higher [f]	246	54.5	1.01	0.91	0.59	1.42	
Marital status							
never married	141	45.4	1.00	1.00	(referent)		0.78
married	595	44.1	1.06	0.84	0.52	1.37	
defacto	167	45.4	1.00	0.77	0.46	1.29	
sep/div/wid [f]	97	44.9	1.02	0.90	0.48	1.66	
Had children							
no	242	55.2	1.00	1.00	(referent)		0.97
yes	757	55.5	1.01	0.99	0.68	1.45	
Smoking status							
yes	206	50.8	1.00	1.00	(referent)		0.32
no	793	56.6	1.27	1.19	0.84	1.67	
SCREENING HISTORY							
Screening status							
underscreened	151	46.5	1.00	1.00	(referent)		0.04
regularly screened	623	57.4	1.55	1.59	1.10	2.30	
overscreened	184	58.8	1.64	1.57	0.99	2.50	
Abnormal Pap							
yes	293	58.6	1.00	1.00	(referent)		0.27
no	706	54.1	0.83	0.84	0.62	1.14	

[a] Weighted sample N = 969 (excludes women in the 'other' screening category)
[b] OR, odds ratios of above average cervical cancer/screening knowledge
[c] odds ratios mutually adjusted for all variables adjusted in table
[d] 95% C.I., confidence interval for true estimate of adjusted odds ratio
[e] statistical significance of adjusted OR
[f] outer reg, rem, vremote = outer regional, remote and very remote, inner reg = inner regional; disadvant = disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

In the adjusted model, differences in knowledge by screening status remained significant and there was virtually no difference between crude and adjusted odds ratios, reflecting a lack of confounding by other variables on screening status in the adjusted model. Women who reported they had regular Pap smears (95% C.I. 0.10–2.30) and overscreened women (95% C.I. 0.99–2.50) had 1.6–fold higher odds ($p = 0.04$) of having above average cervical cancer/screening knowledge levels relative to underscreened women. This difference was also clinically significant as there was a proportional difference of 10% or more between underscreened women (46%) and regular screeners (57%) and overscreened women (59%) with above average knowledge (Table 5.7). This finding confirms a positive relationship between knowledge and participation in cervical cancer/screening.

5.3.3 Summary of Cervical Cancer/Screening Knowledge and Factors Associated with Knowledge Levels

In answer to the question '*What do Queensland women know about cervical cancer/screening and does this differ by socio-demographic factors or cervical screening history?*', whilst study participants correctly identified the purpose of the Pap smear and were familiar with the recommended frequency of participation in the NCSP, there was poor knowledge of the age range of the eligible population and considerable uncertainty expressed by participants about some risk factors for cervical cancer, especially the role of HPV and sexual behaviours.

Bivariate analysis identified limited variation in cervical cancer/screening knowledge levels by socio-demographic factors and a history of an abnormal Pap smear. Differences in knowledge levels were observed by screening status with underscreened women having lower knowledge compared to more regular screeners, which was confirmed by multivariable analyses in which knowledge was found to be an independent predictor of cervical cancer/screening knowledge. The model was limited by poor goodness of fit as the model as a whole only accounted for 2% of the variation in cervical cancer/screening knowledge.

5.4 HPV AWARENESS

To ascertain current awareness of HPV and whether this differed by socio-demographic factors, cervical screening history or cervical cancer/screening knowledge, study participants were asked if they had heard of HPV. Bivariate and multivariable analysis was conducted to assess differences in awareness of HPV by the factors outlined above.

5.4.1 HPV Awareness and Differences by Socio-demographic Factors, Screening History and Knowledge

Approximately two thirds of the study participants (n = 633) indicated they had previously heard of HPV, whilst 367 women (38%) responded 'no' (n = 340) or 'don't know' (n = 27) to this question (Table 5.8).

A statistically significant difference in awareness of HPV following bivariate analysis was observed by educational attainment, children, smoking status, screening history and cervical cancer/screening knowledge (Appendix K). Multivariable analysis was undertaken as a number of independent variables in the bivariate analysis were potential confounders of each other in their relationships with HPV awareness. Factors included in the final model explained 18% (Nagelkerke's R Square = 0.182) of the variation in HPV awareness, which suggests there were other factors not measured in the study that are responsible for much of the variance in HPV awareness.

Following mutual adjustment for all variables in the model, the associations observed in bivariate analysis remained statistically significant for differences in HPV awareness by education, abnormal Pap smear history and cervical cancer/screening knowledge but not for children, smoking status or screening status. Birthplace and marital status showed significant associations with HPV awareness in the adjusted model, but were not associated in the crude models (Table 5.8).

When variables were removed from the model then added back individually to determine the shift in odds ratios of each variable, there was little confounding or variation in odds ratios for education, abnormal Pap smear history and cervical cancer/screening knowledge. The odds ratios for children were more significant when screening status (p = 0.29) and education (p = 0.62) were removed from the model, and less significant when marital status (p = 1.40) was omitted. The odds ratios for smoking were more significant when education (p = 0.71) and marital status (p = 0.62) were omitted from the model whilst screening status was more significant (p = 0.05) when history of an abnormal Pap smear was removed. A decrease in odds ratios and significance for locality was observed when SES, and for education, when country of birth, was omitted from the model. Marital status was less significant when cervical cancer/screening knowledge (p = 0.70) or children (p = 0.10) were removed from the model. The influence of these variables on other variables validated their inclusion in the final model even though there was not always a significant shift in the odds ratios.

On adjustment for other factors associated with HPV awareness, the odds of women who had completed a trade certificate or diploma were 1.9–fold higher (OR 1.93; 95% C.I. 1.28–2.89), and those with a bachelor degree or higher were four-fold higher for having heard of HPV, than women who had completed less than year 10 high school education (OR 4.00; 95% C.I. 2.44–6.57; p <0.0001). In addition, women who had no history of an abnormal Pap smear had lower odds of having heard of HPV (OR 0.68; 95% C.I. 0.48–0.95; p = 0.02) than women with an abnormal screening history. Modelling also confirmed the significant finding that women with above average cervical cancer/screening knowledge had almost three-fold higher odds of having heard of HPV relative to those with below average knowledge (OR 2.95; 95% C.I. 2.21–3.93; p <0.0001).

A decrease in odds ratios between crude and adjusted analyses for the associations between HPV awareness and children, smoking and screening status was observed and were no longer significant, which suggests the model accounted for confounding between the variables included. An increase in odds ratios between crude and adjusted analyses for the association between HPV awareness and living in an inner regional locality was observed; however a decrease was observed for women living in major cities. Women living in inner regional areas had 1.4–fold higher odds of having heard of HPV relative to those living in more remote areas, (OR 1.43; 95% C.I. 0.98–2.10; P = 0.01), that was of borderline statistical significance due to the lower 95% confidence interval being just below 1.

An increase in the odds ratio was observed in awareness of HPV and country of birth, with women born in Australia having 1.5–fold higher odds of having heard of HPV than those born overseas (OR 1.53; 95% C.I. 1.05–2.23; p = 0.03). Marital status also gained significance from p = 0.21 (unadjusted) to p = 0.05 (adjusted), which was reflective of the difference between married women's awareness (66%) when compared with never married women (60%). Married women had almost two-fold higher odds of being aware of HPV (OR 1.90; 95% C.I. 1.12–3.24; p = 0.05) than never married women (Table 5.8).

Table 5.8. Multivariable Relationships between Awareness of HPV and Demographic, Screening History and Knowledge Variables in a Community Sample of 1002[a] women, Queensland, 2008

	HPV Awareness						
	Number women (633)	% aware of HPV (63.0)	Crude OR [b]	Adjusted [c] OR [c]	95% C.I. [d]		Sig [e]
SOCIODEMOGRAPHIC							
Age in 10 yr groups							
20–29	249	63.5	1.00	1.00	(referent)		0.59
30–39	260	63.5	1.00	0.91	0.58	1.41	
40–49	230	64.6	1.05	0.95	0.59	1.51	
50–59	164	66.5	1.14	1.18	0.70	1.99	
60–69	96	53.9	0.67	0.74	0.41	1.35	
Locality							
outer reg, rem, vremote [f]	253	60.3	1.00	1.00	(referent)		0.01
major cities	450	62.1	1.08	0.80	0.55	1.17	
inner reg [f]	296	67.7	1.38	1.43	0.98	2.10	
Socioeconomic status							
quintile 1 (most disadv [f])	176	61.3	1.00	1.00	(referent)		0.08
quintile 2	184	60.5	0.97	0.96	0.60	1.52	
quintile 3	152	56.1	0.81	0.74	0.45	1.20	
quintile 4	194	65.0	1.17	1.21	0.75	1.95	
quintile 5 (least disadv)	294	68.9	1.40	1.45	0.90	2.34	
Australian born							
no	185	59.8	1.00	1.00	(referent)		0.03
yes	814	64.1	1.20	1.53	1.05	2.23	
Educational attainment							
year 10 or below	175	49.6	1.00	1.00	(referent)		<0.0001
year 11or 12	173	57.8	1.40	1.51	0.93	2.44	
cert or diploma [f]	404	63.8	1.80	1.93	1.28	2.89	
Ba degree or higher [f]	246	75.8	3.19	4.00	2.44	6.57	
Marital status							
never married	141	59.8	1.00	1.00	(referent)		0.05
married	595	65.9	1.29	1.90	1.12	3.24	
defacto	167	58.3	0.94	1.18	0.67	2.07	
sep/div/wid [f]	97	61.2	1.06	1.52	0.78	2.98	
Had children							
no	242	69.1	1.00	1.00	(referent)		0.12
yes	757	61.4	0.71	0.71	0.46	1.09	
Smoking status							
yes	206	55.0	1.00	1.00	(referent)		0.27
no	793	65.5	1.55	1.23	0.85	1.76	
CERVICAL SCREENING HISTORY							
Screening status							
underscreened	151	54.7	1.00	1.00	(referent)		0.46
regularly screened	623	63.2	1.43	1.18	0.79	1.77	
overscreened	184	69.4	1.88	1.38	0.83	2.30	
Abnormal Pap history							
yes	293	68.7	1.00	1.00	(referent)		0.02
no	706	61.1	0.71	0.68	0.48	0.95	
KNOWLEDGE							
Cx screen knowledge level							
below average	445	50.6	1.00	1.00	(referent)		<0.0001
above average	554	73.5	2.70	2.95	2.21	3.93	

Table 5.8 continued

[a] Weighted sample N = 969 (excludes women in the 'other' screening category)
[b] OR, odds ratios of having heard of HPV prior to study
[c] odds ratios mutually adjusted for all variables adjusted in table
[d] C.I., confidence interval for true estimate of adjusted odds ratio
[e] statistical significance of adjusted OR
[f] outer reg, rem, vremote = outer regional, remote and very remote, inner reg = inner regional; disadvant = disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

5.4.2 Summary of HPV Awareness and Factors Associated with Awareness

Just under two thirds of Queensland women (63%) had heard of HPV. Following mutual adjustment for all variables included in the model, women who had heard of HPV were most consistently found to be: educated beyond high school, have had an abnormal Pap smear in the past, have above average cervical cancer/screening knowledge, be born in Australia and be married.

Educational attainment and cervical cancer/screening knowledge were also defined as clinically significant. Country of birth, marital status and a history of an abnormal Pap smear result did not meet the definition of clinical significance but the confidence intervals for these factors were consistent with these being independent predictors of HPV awareness. The model as a whole accounted for 18% of the variance in HPV awareness amongst women in this sample.

5.5 HPV KNOWLEDGE

To ascertain what Queensland women know about HPV and if this differed by socio-demographic factors or cervical screening history, women who had heard of HPV were asked a series of true/false questions about HPV. Bivariate and multivariable analysis was conducted to assess differences in knowledge of HPV by these factors. As HPV knowledge was made redundant by HPV awareness as an independent variable, it was not incorporated into further bivariate and multivariate analysis with the outcome variables, HPV vaccination awareness, general vaccination and HPV vaccination attitudes. To assess the relationship of HPV knowledge with these outcomes, they were incorporated at this stage of analysis as independent variables as described in Section 4.5.2.

5.5.1 HPV Knowledge and Differences by Socio-demographic Factors, Screening History and Knowledge

Women's knowledge of HPV was measured using a list of true/false items, which formed the HPV Knowledge Tool. Only those who responded they had heard of HPV

(n=633) were asked to respond to these items, which were presented in randomized order for each study participant. The majority of women (94%) knew about the asymptomatic nature of HPV infection, 85% about the need for some women to have more frequent Pap smears and 77% knew that HPV is a sexually transmitted infection. More than 80% were aware that certain types of HPV can lead to cancer and 71% knew the vaccine could prevent some types of HPV (Table 5.9). HPV knowledge was limited in many aspects with high responses of 'don't know' in the majority of categories (Figure 5.5).

Table 5.9. Responses to HPV Knowledge Items in a Community Sample of 1002[a] women, Queensland, 2008

	True		False		Don't Know	
	N	%	N	%	N	%
A person may be infected with HPV and not know it[1]	**593**	**93.7**	8	1.2	32	5.1
Those with HPV may need Pap smears more often	**539**	**85.2**	32	5.0	62	9.8
Certain types of HPV cause cancer of the cervix	**528**	**83.5**	21	3.4	83	13.1
HPV is spread through sexual intercourse	**485**	**76.6**	64	10.0	84	13.3
There is a vaccine to prevent some types of HPV	**450**	**71.1**	41	6.5	142	22.4
Condoms do not always help protect you against HPV	**386**	**60.9**	148	23.4	99	15.7
If you have HPV, smoking can increase your chance of cervical cancer	**370**	**58.4**	96	15.2	167	26.3
HPV can be cured with antibiotics	108	17.1	**311**	**49.1**	214	33.8
HPV causes women to have abnormal periods	178	28.2	**205**	**32.4**	249	39.4
The Pap smear is a test for HPV	342	54.1	**193**	**30.4**	98	15.5
Women can often clear HPV without treatment	**79**	**12.4**	442	69.9	112	17.7
HPV can cause problems with pregnancy	402	63.5	**58**	**9.1**	173	27.4

Correct response in **boldface**
[a] Weighted sample N = 632 (who had heard of HPV before survey)

Ten percent of women did not think HPV could be spread through sexual activity and only 12% understood the transient nature of HPV infection and that the majority of women may clear the virus spontaneously. Thirty-four percent of women were not sure if antibiotics would cure HPV and 26% were unsure of the role of smoking in increasing women's risk of developing cervical cancer. More than one fifth of respondents were uncertain if there was a vaccine available to prevent HPV (22%) or if HPV caused problems with pregnancy (27%) or menstrual problems (39%). More than half the women surveyed incorrectly thought the Pap smear was a test for HPV (54%) whilst more than 15% were unsure.

When responses were combined to form a score, the average HPV knowledge score was 6.54 (SD = 2.21) and scores were normally distributed (Figure 5.6). One respondent scored the highest possible score of 12 and 13 respondents scored zero, of which about half responded 'don't know' to every item. Overall HPV knowledge was limited in this sample (Table 5.9; Figure 5.5).

Summary HPV knowledge scores were converted to HPV knowledge levels by separating the scores using above and below average (mean) scores as described in Section 4.5.3. A difference of greater than 10% in HPV knowledge levels when stratified by independent variables was determined to be clinically significant.

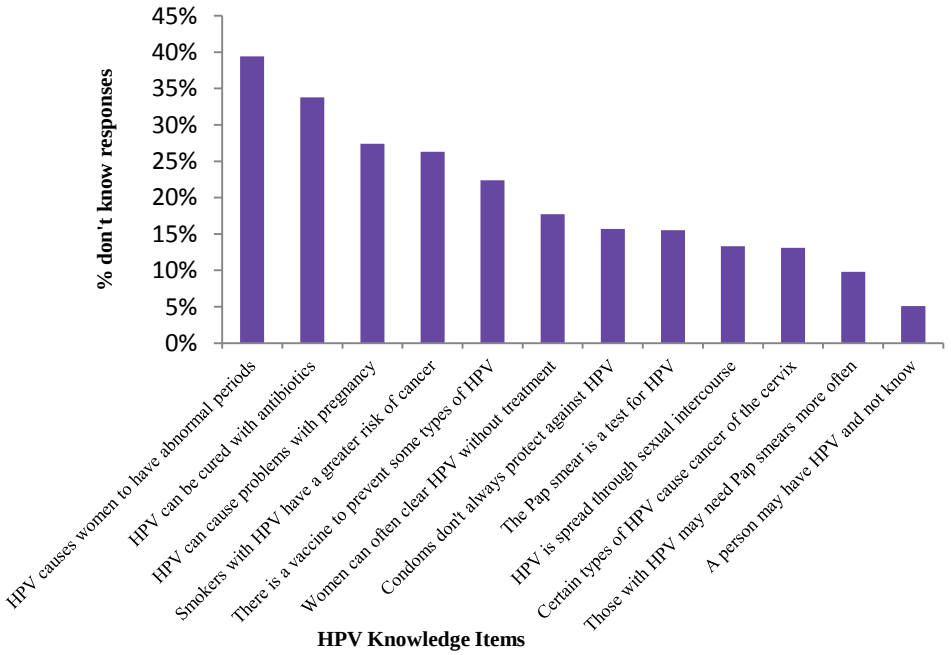

Figure 5.5. Uncertain Responses to HPV Knowledge Items (n=633)

Fifty-six percent of respondents had above average knowledge of HPV. Differences in HPV knowledge following bivariate analysis were observed by age, locality, educational attainment, children, abnormal Pap smear history, cervical cancer/screening knowledge, HPV vaccination awareness and attitudes (Appendix K).

Multivariable analysis was undertaken as a number of independent variables in the bivariate analysis were potential confounders of each other in their relationships with HPV knowledge. Factors included in the final model explained 18% (Nagelkerke's R Square = 0.181) of the variation in HPV knowledge. Following mutual adjustment for all variables in the model, the associations observed in bivariate analysis remained statistically significant for

above average HPV knowledge amongst women in this sample for marital status, cervical cancer/screening knowledge, awareness of the HPV vaccine and HPV vaccination attitudes.

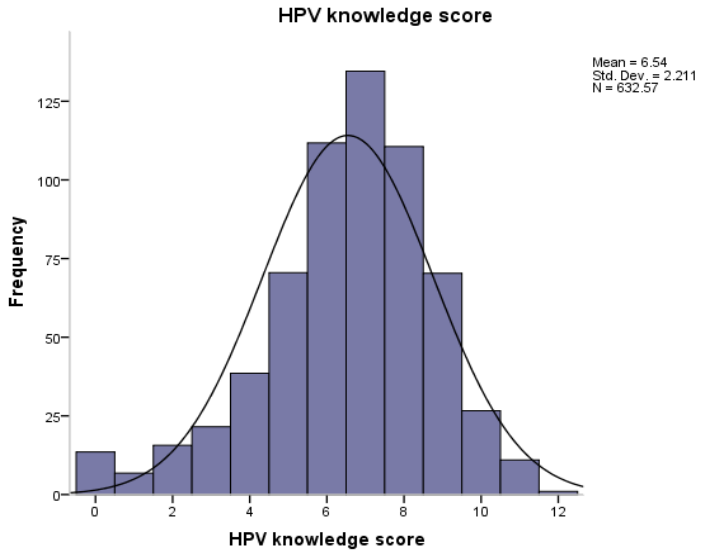

Figure 5.6. Histogram of HPV Knowledge Scores (n=633)

Factors that became non-significant in the adjusted model were age, (although significant differences between the oldest and youngest women were evident), locality, educational attainment, children and a history of an abnormal Pap smear suggesting confounding between factors in the model.

When variables were removed from the model then added back individually to determine the shift in odds ratios of each variable, there was little confounding or variation in odds ratios for cervical cancer/screening knowledge. A decrease in odds ratios of more than 10% was observed for marital status when age was removed from the model but this had minimal impact on statistical significance ($p = 0.006$) and likewise an impact on the significance of the odds ratios for age was observed when marital status was removed from the model ($p = 0.20$). The odds ratios for awareness of the HPV vaccine were more significant when attitudes towards HPV vaccination ($p = 0.0004$) was omitted from the model with an increase in significance for the odds ratios for HPV vaccination when awareness of the HPV vaccine was removed ($p = 0.006$). There was no one variable that seemed to impact on the odds ratios for locality in the adjusted model. A decrease in odds ratios and statistical significance for education ($p = 0.70$) was observed when age was omitted from the model, whilst the odds ratio for children became more significant ($p = 0.16$) when marital status was removed. A number of variables influenced the significance of the odds ratios for abnormal

Pap smear history when removed from the model including screening status (p = 0.06), awareness of the HPV vaccine (p = 0.06) and attitudes towards vaccination (p = 0.04). The influence of these variables on other variables validated their inclusion in the final model even though there was not always a significant shift in odds ratios.

Older women aged over 50 years had lower odds of having above average HPV knowledge. The largest difference was observed for women aged 60 to 69 years when compared with women 20 to 29 years. Women aged over 60 years had much lower odds of having above average HPV knowledge relative to women aged 20 to 29 years (OR 0.38; 95% C.I. 0.17 – 0.84; p = 0.02). Women aged 50 to 59 years also had lower odds of having above average knowledge than those in the youngest age group (OR 0.52; 95% C.I. 0.27–0.99; p = 0.05) and the differences between both groups was clinically significant (Table 5.10). A statistically significant difference was observed between these two groups when compared with the youngest age group at the sub-category level, although age was not found to be a significant predictor in the model overall (p=0.15).

Married and defacto women had lower odds of having above average knowledge relative to never married women but the difference between women who were separated, divorced or widowed was not significant (OR 0.54; 95% C.I. 0.22–1.35). This was in contrast to the finding that married women had higher awareness of HPV than never married women and suggests that awareness does not equate to knowledge.

The differences between all groups relative to women who had never married were also of clinical significance. Modelling also confirmed the significant finding that women with above average cervical cancer/screening knowledge had two-fold higher odds of having above average knowledge about HPV (O.R 2.19; 95% C.I. 1.52–3.15; p <0.0001) relative to women with below average cervical cancer/screening knowledge (Table 5.10).

Having heard of the HPV vaccine and having positive attitudes towards the HPV vaccine were also confirmed as being associated with HPV knowledge, although there was a decrease in the odds ratios for HPV vaccination following mutual adjustment for all variables in the model. Women who had heard of the HPV vaccine had three-fold higher odds of having above average HPV knowledge relative to those who had not (OR 3.19; 95% C.I. 1.55–6.56; P <0.0001), whilst those with positive HPV vaccination attitudes had 1.7–fold higher odds of having higher HPV knowledge relative to those with negative attitudes (OR 1.69; 95% C.I. 1.05–2.73; P = 0.03).

Table 5.10. Multivariable Relationships between Above Average HPV Knowledge and Demographic, Screening History, Knowledge and Attitude Variables in a Community Sample of 1002[a] Women, Queensland, 2008

	HPV knowledge			Adjusted [c]			
	Number women (633)	% above average (56)	Crude OR [b]	OR[c]	95% C.I. [d]		Sig [e]
SOCIO-DEMOGRAPHIC							
Age in 10 yr groups							
20–29	158	67.3	1.00	1.00	(referent)		0.14
30–39	165	56.3	0.63	0.72	0.40	1.29	
40–49	148	54.6	0.58	0.67	0.37	1.22	
50–59	109	49.9	0.48	0.52	0.27	0.99	
60–69	52	37.4	0.29	0.38	0.17	0.84	
Locality							
outer reg, rem, vremote [f]	153	51.0	1.00	1.00	(referent)		0.80
major cities	279	62.0	1.57	1.18	0.72	1.93	
inner reg [f]	201	51.7	1.04	1.17	0.73	1.87	
Socioeconomic status							
quintile 1 (most disadv [f])	108	52.3	1.00	1.00	(referent)		0.67
quintile 2	111	51.1	0.95	0.99	0.55	1.77	
quintile 3	85	52.1	0.99	1.04	0.55	1.96	
quintile 4	126	53.8	1.06	0.88	0.49	1.60	
quintile 5 (least disadv)	202	63.6	1.60	1.32	0.73	2.40	
Australian born							
no	111	59.7	1.00	1.00	(referent)		0.17
yes	522	55.2	0.83	0.71	0.43	1.16	
Educational attainment							
year 10 or below	87	43.1	1.00	1.00	(referent)		0.70
year 11or 12	100	56.5	1.72	0.97	0.49	1.90	
cert or diploma [f]	258	57.2	1.76	1.26	0.72	2.21	
Ba degree or higher [f]	187	60.5	2.02	1.22	0.66	2.27	
Marital status							
never married	84	78.6	1.00	1.00	(referent)		0.004
married	392	52.7	0.30	0.42	0.20	0.89	
defacto	97	50.3	0.28	0.24	0.11	0.53	
sep/div/wid [f]	59	54.9	0.33	0.54	0.22	1.35	
Had children							
no	167	66.5	1.00	1.00	(referent)		0.55
yes	465	52.2	0.55	0.86	0.53	1.40	
Smoking status							
yes	113	55.3	1.00	1.00	(referent)		0.57
no	519	56.1	1.03	1.15	0.71	1.89	
CERVICAL SCREENING HISTORY							
Screening status							
underscreened	82	58.2	1.00	1.00	(referent)		0.84
regularly screened	394	53.5	0.83	0.96	0.56	1.67	
overscreened	128	59	1.03	1.11	0.57	2.14	
Abnormal Pap history							
yes	201	61.6	1.00	1.00	(referent)		0.09
no	431	53.4	0.71	0.71	0.47	1.06	
KNOWLEDGE AND AWARENESS							
Cx screen knowledge level							
below average	225	41.4	1.00	1.00	(referent)		<0.0001
above average	407	64.1	2.52	2.19	1.52	3.15	
Heard of HPV vaccine							
no	51	26.6	1.00	1.00	(referent)		<0.0001
yes	581	58.6	3.89	3.19	1.55	6.56	

Table 5.10 continued

ATTITUDES							
General vaccine attitudes							
negative	67	51.2	1.00	1.00	(referent)		0.74
positive	565	56.6	1.24	0.90	0.48	1.68	
HPV vaccine attitudes							
negative	137	41.3	1.00	1.00	(referent)		0.03
positive	495	60.1	2.14	1.69	1.05	2.73	

[a] Weighted sample N = 632 (who had heard of HPV before survey)
[b] OR, odds ratios of having above average HPV knowledge
[c] odds ratios mutually adjusted for all variables adjusted in table
[d] C.I., confidence interval for true estimate of adjusted odds ratio
[e] statistical significance of adjusted OR
[f] outer reg, rem, vremote = outer regional, remote and very remote, inner reg = inner regional; disadvant = disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

5.5.2 Summary of HPV Knowledge and Factors Associated with Above and Below Average Knowledge

In response to the research question, *'What do Queensland women know about HPV and does this differ by socio-demographic factors, cervical screening history, awareness and attitudes?'*, this study found that women had limited knowledge and high levels of uncertainty about HPV.

Following mutual adjustment for all variables included in the model, the factors associated with above average HPV knowledge amongst women in this sample were age, marital status, cervical cancer/screening knowledge, HPV vaccination awareness and attitudes. Women with below average HPV knowledge were most consistently found to be: aged over 50 years; in married or defacto relationships; have below average cervical cancer/screening knowledge; be unaware of the HPV vaccine and have negative attitudes towards HPV vaccination. The model as a whole accounted for 18% of the variance in HPV knowledge amongst women in this sample.

5.6 HPV VACCINE AWARENESS

To determine how many Queensland women were aware of the HPV vaccine and where they heard about it, study participants completed questions pertaining to having heard of the HPV vaccine, the source of this information and if they had been vaccinated against HPV. All women were asked if they had heard of the cervical cancer or HPV vaccine prior to being asked further questions. The majority of study participants (86%) indicated they had heard of the vaccine, whilst less than one percent was unsure. Of the 863 women who had

heard of the vaccine, 112 women (13%) said they had received the vaccine whilst three women were unsure whether they had been vaccinated (Table 5.11).

Table 5.11. Knowledge of HPV Vaccine and Vaccination Status in a Community Sample of 1002[a] Women, Queensland, 2008

HPV Vaccine Awareness and Status						
	Yes		No		Don't know	
	N	%	N	%	N	%
Before today, have you heard of the vaccine for cervical cancer or HPV?	863	86.3	134	13.4	2	0.2
Have you had the vaccine? [b]	112	13.0	747	86.6	3	0.4

[a] Weighted sample N = 999
[b] N = 863 - Only asked this question if had heard of the vaccine

Whilst 87% of women indicated they had heard of the cervical cancer or HPV vaccine when asked this question, it is interesting to note only 71% of women agreed there was a vaccine to prevent certain types of HPV in the HPV Knowledge Tool, which suggests the vaccine is more commonly recognised as preventing cervical cancer rather than HPV per se.

Women were asked where they had heard of the vaccine and were able to give multiple responses. Mass media was most commonly identified as the source of vaccine awareness with television being the highest reported source by 566 women followed by 208 women who had heard of it via the newspaper. Doctors and clinics were the source of information listed by over 200 women, with nurses and health workers identified as sources of information by 22 respondents. The Internet, letters or workplaces were not frequently reported sources of information at the time of this survey. Other sources uncommonly identified, included the back of toilet doors, through research studies or at university and Professor Ian Frazer (Figure 5.7).

5.6.1 HPV Vaccination Awareness and Differences by Socio-demographic Factors, Screening History and Knowledge

Differences in HPV vaccination awareness following bivariate analysis were observed by age, country of birth, educational attainment, children, screening status, cervical screening knowledge and HPV awareness (Appendix K).

Multivariable analysis was undertaken as a number of independent variables in the bivariate analysis were potential confounders of each other in their relationships with awareness of the HPV vaccine.

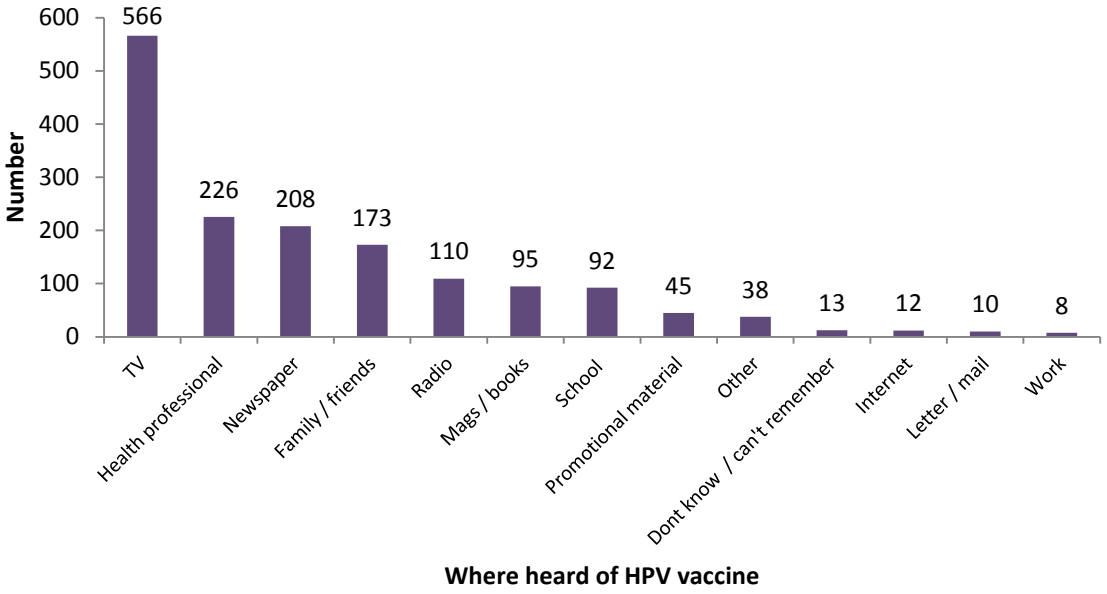

Figure 5.7. Sources of HPV Vaccine Information (n=863)

Factors included in the final model explained 19% (Nagelkerke's R Square = 0.193) of the variation in awareness of the HPV vaccine. Following mutual adjustment for all variables included in the model, the factors associated with HPV vaccination awareness amongst women in this sample were age, country of birth and abnormal Pap smear history, cervical cancer/screening knowledge and HPV awareness. Differences in awareness by educational attainment and having had children were no longer of statistical significance.

When variables were removed from the model then added back individually to determine the shift in odds ratios of each variable, there was little confounding or variation in odds ratios for age, born in Australia, abnormal Pap history or having heard of HPV. An increase in odds ratios of more than 10% was observed for cervical cancer/screening knowledge when HPV awareness was removed from the model and had a large impact on statistical significance ($p = 0.002$). The odds ratios for educational attainment increased when HPV awareness was omitted from the model, although this did not reach statistical significance ($p = 0.09$). Minor changes in odds ratios and significance were noted for marital status, none of which were significant when HPV awareness, Australian born and age were individually removed from the model, whilst the odds ratio for children became more significant ($p = 0.10$) when age was removed. All variables were retained in the final model.

Table 5.12. Multivariable Relationships between Awareness of the HPV Vaccine and Demographic, Screening History and Knowledge Variables in a Community Sample of 1002[a] Women, Queensland, 2008

	Awareness of the HPV vaccine					
				Adjusted [c]		
	Number women	% aware vaccine (86.3)	Crude OR[b]	OR[c]	95% C.I. [d]	Sig [e]
SOCIODEMOGRAPHIC						
Age in 10 yr groups						
20–29	249	91.7	1.00	1.00	(referent)	<0.0001
30–39	260	82.4	0.42	0.32	0.16 0.63	
40–49	230	91.3	0.95	0.83	0.39 1.79	
50–59	164	86.0	0.56	0.52	0.24 1.13	
60–69	96	71.8	0.23	0.24	0.11 0.54	
Locality						
outer reg, rem, vremote [f]	252	84.1	1.00	1.00	(referent)	0.14
major cities	450	88.2	1.42	1.67	0.98 2.83	
inner reg [f]	297	85.4	1.11	1.11	0.67 1.86	
Socioeconomic status						
quintile 1 (most disadv [f])	176	84.0	1.00	1.00	(referent)	0.96
quintile 2	184	84.7	1.05	0.92	0.49 1.72	
quintile 3	152	83.2	0.95	0.92	0.47 1.78	
quintile 4	194	88.6	1.48	1.16	0.59 2.27	
quintile 5 (least disadv)	294	88.9	1.52	0.95	0.49 1.85	
Australian born						
no	185	80.0	1.00	1.00	(referent)	0.001
yes	814	87.8	1.80	2.27	1.39 3.71	
Educational attainment						
year 10 or below	175	81.3	1.00	1.00	(referent)	0.40
year 11or 12	173	84.7	1.28	1.32	0.69 2.54	
cert or diploma [f]	404	86.7	1.50	1.36	0.79 2.35	
Ba degree or higher [f]	246	90.6	2.22	1.83	0.91 3.68	
Marital status						
never married	141	86.3	1.00	1.00	(referent)	0.54
married	595	86.5	1.01	1.54	0.72 3.27	
defacto	167	89.2	1.30	1.59	0.68 3.70	
sep/div/wid [f]	97	80.7	0.66	1.13	0.46 2.79	
Had children						
no	242	90.3	1.00	1.00	(referent)	0.42
yes	757	85.1	0.61	0.77	0.41 1.45	
Smoking status						
yes	206	85.0	1.00	1.00	(referent)	0.91
no	793	86.7	1.14	0.97	0.58 1.63	
CERVICAL SCREENING HISTORY						
Screening status						
underscreened	151	83.0	1.00	1.00	(referent)	0.96
regularly screened	623	85.9	1.25	1.05	0.62 1.79	
overscreened	184	90.9	2.04	1.12	0.54 2.32	
Abnormal Pap history						
yes	293	93.2	1.00	1.00	(referent)	<0.0001
no	706	83.5	0.37	0.35	0.20 0.61	
KNOWLEDGE AND AWARENESS						
Cx screen knowledge level						
below average	445	82.3	1.00	1.00	(referent)	0.05
above average	554	89.6	1.84	1.52	1.01 2.30	
HPV awareness						
no	367	76.7	1.00	1.00	(referent)	<0.0001
yes	633	91.9	3.45	2.73	1.79 4.17	

Table 5.12 continued

[a] Weighted sample = 999
[b] OR, odds ratios of below average cervical cancer/screening knowledge
[c] odds ratios mutually adjusted for all variables adjusted in table
[d] C.I., confidence interval for true estimate of adjusted odds ratio
[e] statistical significance of adjusted OR
[f] outer reg, rem, vremote = outer regional, remote and very remote, inner reg = inner regional; disadvant = disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

Women aged over 60 years had lower odds (OR 0.24; 95% C.I. 0.11 – 0.54) as did women aged 30 to 39 years of age (OR 0.32; 95% C.I. 0.16 – 0.63; $p < 0.0001$) of having heard of the HPV vaccine relative to women 20 to 29 years old. Women born in Australia had more than two-fold higher odds of having heard of the HPV vaccine relative to those born overseas, which gained significance when other factors were included in the model (OR 2.27; 95% C.I. 1.39 – 3.71; $p = 0.001$).

There was little change in variation following mutual adjustment of all variables in the model by abnormal Pap smear history with women who had not had a previous abnormality remaining at lower odds of having heard of the HPV vaccine relative to those who had (OR 0.35; 95% C.I. 0.20 – 0.61; $p < 0.0001$). A decrease in odds ratios was observed for cervical cancer/screening knowledge and HPV awareness. Women with above average cervical cancer/screening knowledge had 1.5–fold higher odds of being aware of the HPV vaccine relative to those with below average knowledge (OR 1.52; 95% C.I. 1.01 – 2.30) and those who were aware of HPV had 2.7–fold higher odds of being aware of the vaccine relative to those who were not (OR 2.73; 95% C.I. 1.79 – 4.17; $p = 0.05$).

5.6.2 Summary of Factors Associated with HPV Vaccine Awareness

In response to the research question about Queensland women's awareness of the HPV vaccine, the sources of this awareness and if awareness differed by socio-demographic factors, screening history, knowledge or awareness, over 86% of women had heard of the HPV vaccine and the most commonly cited sources of this awareness was through mass media.

Following mutual adjustment for all variables included in the model, the factors associated with awareness of the HPV vaccine amongst women in this sample were age, country of birth, abnormal Pap smear history, awareness of HPV and cervical cancer/screening knowledge.

Women with lowest awareness of the HPV vaccine were most consistently found to be aged 30 to 39 years and 60 to 69 years, be born overseas, have never had an abnormal Pap smear, have not heard of HPV and have below average cervical cancer/screening knowledge. These factors were also of clinical significance, with the exception of cervical cancer/screening knowledge, although the confidence intervals for this factor were consistent with it being an independent predictor of HPV vaccination awareness. The model as a whole accounted for 19% of the variance in HPV vaccination awareness amongst women in this sample.

5.7 HPV VACCINATION ATTITUDES

To determine Queensland women's attitudes towards HPV vaccination and whether they differed by socio-demographic factors, screening history, cervical cancer/screening knowledge or awareness, study participants firstly completed questions pertaining to their attitudes towards vaccination in general followed by their attitudes towards the HPV vaccine itself. This was to obtain a sense of women's views about vaccination in general or whether there was a difference in their attitudes that could be attributed specifically to the HPV vaccine. As described in Section 4.1, following a brief statement explaining the HPV vaccine, all participants in this study completed the attitude questions.

5.7.1 Attitudes towards Vaccination in General

The majority of women who responded to the survey reported positive attitudes to vaccination in general. As outlined in Table 5.13, most respondents strongly agreed or agreed (96%) that "Prevention is better than cure for cervical cancer" with few women feeling neutral, negative or expressing uncertainty about this item. Similar results were observed about whether "Vaccines are an important way to prevent disease" with similar numbers of women strongly agreeing and agreeing (n = 962) with this statement.

Women also were positive about childhood vaccination with most respondents strongly agreeing or agreeing (92%) that "Everyone should be vaccinated against preventable diseases in childhood", although five percent of women disagreed or strongly disagreed (n = 46) with this statement. Eighty-six percent of women agreed or strongly agreed with the statement - "All children should be vaccinated against preventable conditions while they are still babies" (Table 5.13).

There was less agreement with the statement "Vaccines that have been approved by the Health Department are safe" with 79% of women agreeing or strongly agreeing, 126 women

(13%) neither agreeing nor disagreeing and seven percent of women disagreeing or strongly disagreeing with this statement. Cost and access issues were important factors for about one fifth of respondents, with 23% of the sample agreeing or strongly agreeing that the cost of vaccination would influence their decision to have a child vaccinated and 40% indicating the convenience of the venue where the vaccine is given would also influence the decision to have a child vaccinated. There were more polarised views regarding concern about side effects with 49% of the sample strongly agreeing or agreeing that they worried about the side effects of vaccines for children, 41% disagreeing or strongly disagreeing and nine percent indicating they neither agreed nor disagreed with this statement (Table 5.13).

Table 5.13. General Vaccination Attitudes in a Community Sample of 1002 [s] Women, Queensland, 2008

	General Vaccination Attitudes						
	Strongly agree n (%)	**Agree n (%)**	**Neither agree nor disagree n (%)**	**Disagree n (%)**	**Strongly disagree n (%)**	**Don't know n (%)**	**Refused answer n (%)**
Prevention is better than cure for cervical cancer	604 (60.4)	350 (35.1)	16 (1.6)	18 (1.8)	4 (0.4)	7 (0.7)	0 0.0)
Vaccines are an important way to prevent disease	557 (55.7)	405 (40.6)	16 (1.6)	15 (1.5)	4 (0.4)	1 (0.1)	0 0.0)
Everyone should be vaccinated against preventable diseases in childhood	513 (51.4)	404 (40.5)	32 (3.2)	34 (3.4)	12 (1.2)	2 (0.2)	1 (0.1)
Vaccines that have been approved by the Health Department are safe	219 (21.9)	571 (57.1)	126 (12.6)	55 (5.5)	16 (1.6)	14 (1.4)	0 0.0)
All children should be vaccinated against preventable conditions while they are still babies	422 (42.2)	431 (43.2)	61 (6.1)	56 (5.6)	17 (1.7)	13 (1.3)	0 0.0)
The costs involved would influence my decision to have a child of mine vaccinated	66 (6.6)	158 (15.8)	28 (2.8)	412 (41.2)	326 (32.6)	7 (0.7)	2 (0.2)
The convenience of the venue where the vaccine is given would influence my decision to have a child of mine vaccinated	105 (10.5)	291 (29.1)	46 (4.6)	357 (35.7)	182 (18.2)	17 (1.7)	2 (0.2)
I worry about the side effects of vaccines for children	110 (11.0)	377 (37.7)	95 (9.5)	342 (34.2)	64 (6.4)	11 (1.1)	1 (0.1)

[a] Weighted sample = 999

5.7.2 General Vaccination Attitudes and Differences by Socio-demographic Factors, Screening History, Knowledge and Awareness

An overall score for attitudes towards vaccination in general was obtained as outlined in Section 4.5.3, which was converted into a positive or negative score. The sample was very positive towards vaccination in general (88% positive attitudes). There was very little variation in attitudes towards vaccination in general observed by any variables with the exception of smoking status. Eighty nine percent of non-smokers (Likelihood $Chi^2 = 4.35$; df = 1; p = 0.04), were positive towards vaccination in general compared to 84% of smokers (Appendix K). This difference was no longer statistically significant when adjusted for other variables following multivariable modelling (OR 1.43; 95% C.I. 0.88 – 2.32; p = 0.15) – data not shown.

5.7.3 Attitudes towards the HPV Vaccine

The second vaccination attitude scale related specifically to items concerning HPV vaccination. As demonstrated in Table 5.14, the majority of women who responded to the survey reported positive attitudes to HPV vaccination. Most respondents strongly disagreed or disagreed (84%) with the statement "If I had a 12 year old daughter I would not want her to be vaccinated against HPV" and 85% did not agree that "Vaccinating young women and girls against HPV would encourage them to become sexually active".

Many women (64%) felt they needed more information before deciding whether to vaccinate their daughter against HPV, although one third of the sample (33%) did not agree with this statement. The role of medical practitioners in promoting the vaccine was important for 86% of the sample who strongly agreed or agreed with the statement "If I had a 12 year old daughter and my doctor thinks it is a good idea, I would have her vaccinated against HPV". The proportion of women who strongly agreed with this statement was the highest observed for any item in this scale.

There was some uncertainty amongst the sample for the items "There is more risk involved in being vaccinated than in having HPV" and "The cervical cancer vaccine works best when it is given before a young woman becomes sexually active" with 11% and 19% (respectively) of women responding "don't know" to these items (Table 5.14).

Of those who chose a category that indicated their attitudes to these items, 70% disagreed or strongly disagreed having the vaccine would be more risky than having HPV, although 11% agreed/strongly agreed this was the case and 11% were neutral in their

response. Sixty-five percent agreed or strongly agreed that the vaccine works best if given prior to sexual debut, with 10% responding neutrally to this item, six percent disagreeing or strongly disagreeing with this statement and 19% expressing uncertainty.

Table 5.14. HPV Vaccination Attitudes in a Community Sample of 1002 [a] Women, Queensland, 2008

	HPV Vaccination Attitudes						
	Strongly agree n (%)	**Agree n (%)**	**Neither agree nor disagree n (%)**	**Disagree n (%)**	**Strongly disagree n (%)**	**Don't know n (%)**	**Refused answer n (%)**
If I had a 12 year old daughter I would not want her to be vaccinated against HPV	16 (1.6)	53 (5.8)	38 (3.8)	549 (54.9)	296 (29.6)	46 (4.6)	2 (0.2)
Vaccinating young women and girls against HPV would encourage them to become sexually active	12 (1.2)	75 (7.5)	39 (3.9)	585 (58.6)	265 (26.5)	22 (2.1)	1 (0.1)
If I had a 12 year old daughter I would need more information before I could decide whether she should be vaccinated against HPV	245 (24.5)	398 (39.9)	24 (2.4)	240 (24.0)	87 (8.7)	4 (0.4)	1 (0.1)
If I had a 12 year old daughter and my doctor thinks it is a good idea, I would have her vaccinated against HPV	334 (33.5)	527 (52.7)	47 (4.7)	63 (6.3)	17 (1.7)	10 (1.0)	1 (0.1)
There is more risk involved in being vaccinated than in having HPV	27 (2.7)	75 (7.5)	82 (8.2)	485 (48.5)	218 (21.8)	112 (11.2)	1 (0.1)
The cervical cancer vaccine works best when it is given before a young woman becomes sexually active	177 (17.7)	470 (47.0)	102 (10.3)	44 (4.4)	14 (1.4)	191 (19.1)	1 (0.1)

[a] Weighted sample = 998

A similar scoring system to that used for General Vaccination Attitudes was used for the scoring of attitudes towards the HPV vaccine as outlined in Section 4.5.3. One respondent was excluded from this analysis as she responded "don't know" to all items in this attitude scale and therefore did not have a score for this scale.

Overall 74% of the sample had positive attitudes towards HPV vaccination. A higher proportion of women had positive attitudes towards vaccination than the HPV vaccine with 69% of women having positive attitudes to both. One-hundred and seventeen women were negative towards vaccination in general; however more than twice as many women (n = 260)

expressed negative attitudes towards the HPV vaccine. There were only seven percent of women in the study who had negative attitudes towards vaccination in general and the HPV vaccine. Almost one fifth of study participants (193 women) had positive attitudes towards vaccination in general but was negative towards HPV vaccination (Figure 5.8).

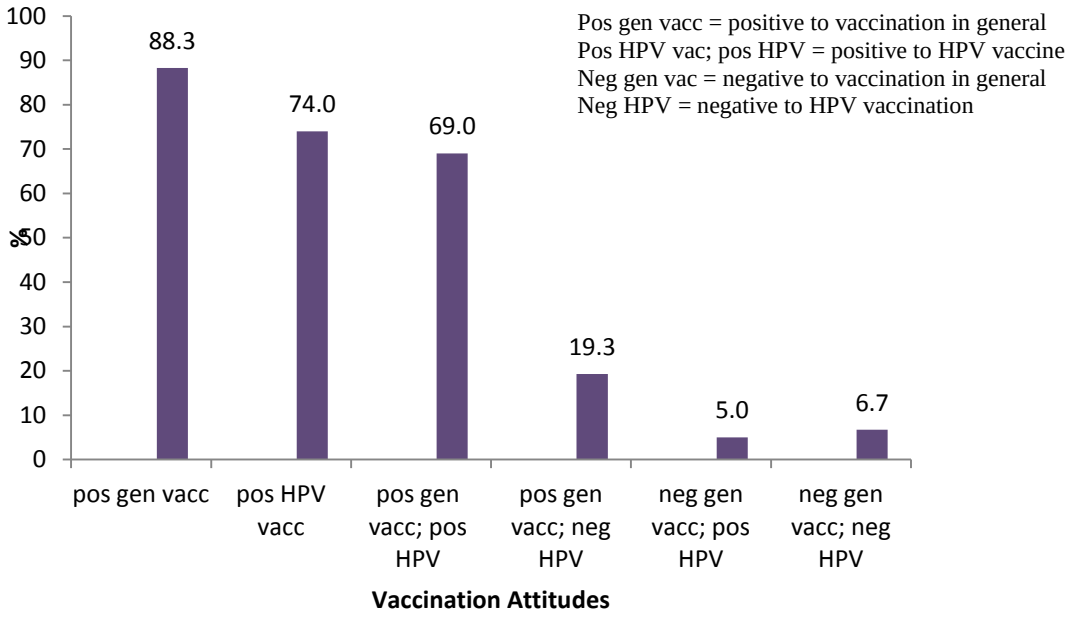

Figure 5.8. Attitudes towards General Vaccination and the HPV Vaccine (n=999)

These findings should be viewed in the context of how negative attitudes were derived (Section 4.5.3) as there were higher proportions of women with uncertainty about some items in the HPV attitude scale who were allocated a score of zero (a negative score) for these responses (Figure 5.9, Figure 5.10). These figures show much higher responses of 'don't know' to HPV vaccination attitude items than general vaccination items indicating higher uncertainty amongst women in this study to the HPV vaccine than other vaccines.

5.7.4 HPV Vaccination Attitudes and Differences by Socio-demographic Factors, Screening History, Knowledge, Awareness and Attitudes

Attitudes towards HPV vaccination were found following bivariate analysis to differ by SES, country of birth, abnormal Pap smear history, cervical cancer/screening knowledge, having heard of HPV and the HPV vaccine and general vaccination attitudes (Appendix K).

Multivariable analysis was undertaken as a number of independent variables in the bivariate analysis were potential confounders of each other in their relationships with

attitudes towards the HPV vaccine. Factors included in the final model explained 24% (Nagelkerke's R Square = 0.240) of the variation in attitudes towards the HPV vaccine.

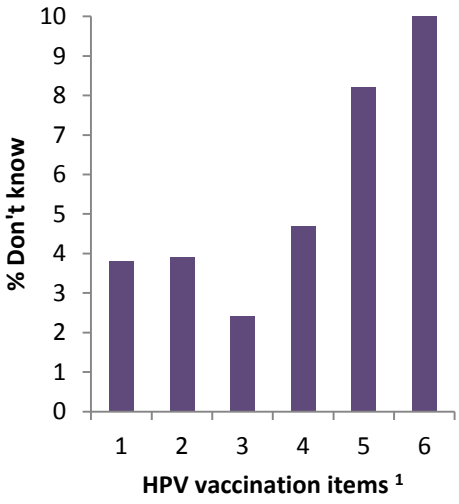

Figure 5.9. Proportion of 'don't know' Responses to HPV Vaccination Attitude Items (n=998)
[1]Item numbers listed in Appendix H

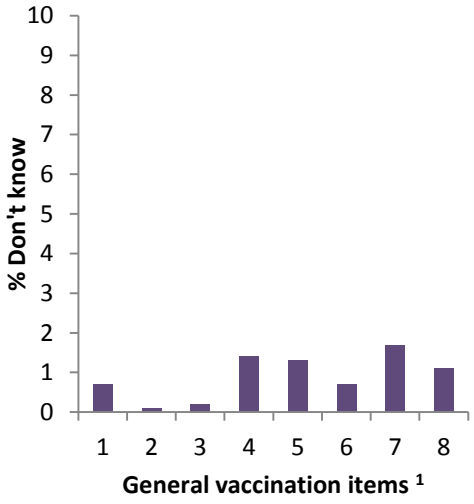

Figure 5.10. Proportion of 'don't know' Responses to General Vaccination Attitude Items (n=999)
[1]Item numbers listed in Appendix H

Following mutual adjustment for all variables in the model, the associations observed in bivariate analysis remained statistically significant for positive HPV vaccination attitudes for SES, country of birth, a history of an abnormal Pap smear, cervical cancer/screening knowledge, HPV vaccine awareness and attitudes towards vaccination in general but not for awareness of HPV (Table 5.15).

When variables were removed from the model then added back individually to determine the shift in odds ratios of each variable, there was little confounding or variation in odds ratios for SES, born in Australia, HPV vaccine awareness and attitudes towards vaccination in general. Variations in the significance of adjusted odds ratios were observed for abnormal Pap history when HPV awareness ($p < 0.0001$) and SES ($p = 0.001$) were removed from the model. Odds ratios were also more significant for cervical cancer/screening knowledge when HPV awareness and HPV vaccine awareness ($p = 0.0002$, respectively) and screening status ($p = 0.0004$) were individually removed from the model. The odds ratios for HPV awareness increased when HPV vaccine awareness ($p = 0.06$) and cervical cancer/screening knowledge ($p = 0.5$) were each removed from the model. The influence of these variables on other variables validated their inclusion in the final model even though there was not always a significant shift in odds ratios.

Table 5.15. Multivariable Relationships between HPV Vaccination Attitudes and Demographic, Screening History and Knowledge Variables in a Community Sample of 1002[a] Women, Queensland, 2008

	HPV Vaccination Attitudes					
	Number women (998)	% Positive attitudes (74.0)	Crude OR [b]	Adjusted [c] OR[c]	95 C.I [d]	Sig e
SOCIODEMOGRAPHIC						
Age in 10 yr groups						
20–29	249	77.1	1.00	1.00	(referent)	0.53
30–39	260	73.2	0.81	0.77	0.46 1.29	
40–49	230	76.2	0.95	0.99	0.57 1.71	
50–59	163	71.9	0.76	0.69	0.38 1.25	
60–69	96	66.1	0.58	0.68	0.35 1.35	
Locality						
outer reg, rem, vremote [f]	252	70.5	1.00	1.00	(referent)	0.53
major cities	449	75.5	1.29	1.10	0.71 1.70	
inner reg [f]	297	74.7	1.23	1.28	0.83 1.97	
Socioeconomic status						
quintile 1 (most disadv [f])	176	77.8	1.00	1.00	(referent)	0.001
quintile 2	184	66.3	0.56	0.45	0.27 0.77	
quintile 3	152	64.9	0.53	0.50	0.28 0.88	
quintile 4	194	78.6	1.05	1.12	0.63 2.00	
quintile 5 (least disadv)	293	78.2	1.03	0.94	0.53 1.65	
Australian born						
no	185	63.5	1.00	1.00	(referent)	0.01
yes	813	76.4	1.86	1.80	1.19 2.73	
Educational attainment						
year 10 or below	175	69.1	1.00	1.00	(referent)	0.33
year 11or 12	173	75.6	1.38	1.20	0.68 2.10	
cert or diploma [f]	403	76.2	1.43	1.43	0.89 2.29	
Ba degree or higher [f]	246	73.1	1.22	1.02	0.59 1.77	
Marital status						
never married	141	76.6	1.00	1.00	(referent)	0.96
married	594	74.1	0.88	1.03	0.56 1.90	
defacto	167	74.1	0.88	0.91	0.48 1.74	
sep/div/wid [f]	97	69.0	0.68	0.98	0.45 2.10	
Had children						
no	242	76.7	1.00	1.00	(referent)	0.58
yes	756	73.1	0.83	0.87	0.54 1.41	
Smoking status						
yes	206	72.7	1.00	1.00	(referent)	0.84
no	792	74.3	1.09	0.96	0.63 1.46	
SCREENING HISTORY						
Screening status						
underscreened	151	67.8	1.00	1.00	(referent)	0.59
regularly screened	623	75.0	1.43	1.15	0.74 1.78	
overscreened	183	77.6	1.64	0.92	0.52 1.62	
Abnormal Pap history						
yes	292	83.1	1.00	1.00	(referent)	0.0003
no	706	70.2	0.48	0.46	0.31 0.70	
KNOWLEDGE AND AWARENESS						
Cx screen knowledge level						
below average	444	66.9	1.00	1.00	(referent)	0.001
above average	554	79.7	1.94	1.80	1.28 2.52	
Heard HPV						
no	366	66.4	1.00	1.00	(referent)	0.26
yes	633	78.3	1.83	1.23	0.86 1.75	

Table 5.15 continued

Heard HPV vaccine							
no	137	49.1	1.00	1.00	(referent)		<0.0001
yes	862	77.9	3.66	2.78	1.80	4.29	
ATTITUDES							
General vaccination attitudes							
negative	117	42.4	1.00	1.00	(referent)		<0.0001
positive	881	78.2	4.85	5.85	3.75	9.12	

[a] Weighted sample = 999
[b] OR, odds ratios of below average cervical cancer/screening knowledge
[c] odds ratios mutually adjusted for all variables adjusted in table
[d] C.I., confidence interval for true estimate of adjusted odds ratio
[e] statistical significance of adjusted OR
[f] outer reg, rem, vremote = outer regional, remote and very remote, inner reg = inner regional; disadvant = disadvantaged; Ba degree = bachelor degree; sep/div/wid = separated, divorced, widowed

When compared with women living in areas of most socio-economic disadvantage, women in quintiles two (OR 0.45; 95% C.I. 0.27–0.77) and three (OR 0.50; 95% C.I. 0.28–0.88) had lower odds of having positive attitudes towards vaccination (p =0.001). Variation in HPV vaccination attitudes by country of birth remained significant with women born in Australia having 1.8–fold higher odds of having positive HPV vaccine attitudes relative to women born overseas (OR 1.80; 95% C.I. 1.19–2.73; p =0.01). Study participants who had never had an abnormal Pap smear history had lower odds of having positive HPV vaccination attitudes relative to those who had experienced an abnormal result (OR 0.46; 95% C.I. 0.31–0.70; p <0.0001).

A significant difference in knowledge, awareness and attitudes towards HPV vaccination was also confirmed through multivariate modelling. Women who had above average cervical cancer/screening knowledge had 1.8–fold higher odds of having positive attitudes towards the vaccine (OR 1.80; 95% C.I. 1.28–2.52; p = 0.001) relative to those with below average knowledge. A decrease in odds was observed by awareness of HPV and was no longer significant when adjusted for other factors included in the model (OR 1.23; 95% C.I. 0.86–1.75; p =0.26). However, awareness of the vaccine remained a significant predictor of positive attitudes with women who had heard of the vaccine prior to participating in the survey having 2.8–fold higher odds of having positive HPV vaccine attitudes relative to those who had not (OR 2.78; 95% C.I. 1.80–4.29; p < 0.0001).

A highly significant difference was also confirmed through multivariate modelling between participants who had expressed positive attitudes towards vaccination in general. These women had 5.8–fold higher odds of having positive attitudes towards the HPV vaccine

(OR 5.85; 95% C.I. 3.75–9.12; p <0.0001) relative to those who had negative attitudes about vaccination in general.

5.7.5 Summary of Factors Associated with HPV Vaccination Attitudes

In response to the question – '*What are Queensland women's attitudes towards HPV vaccination and does this differ by socio-demographic factors, screening history, cervical cancer/screening knowledge or awareness*?' 74% of women in this study were found to have positive attitudes towards HPV vaccination. The majority of women would want their daughter to be vaccinated against HPV, especially if recommended by their doctor and did not believe vaccinating young girls would encourage them to become sexually active. Most women indicated the need for more information about the vaccine and some expressed uncertainty about the vaccine in relation to its safety and whether the vaccine was more effective if given prior to sexual debut.

Following mutual adjustment for all variables included in the model, the factors associated with positive attitudes towards the HPV vaccine were country of birth, abnormal Pap smear history, cervical cancer/screening knowledge and HPV vaccination awareness and positive HPV vaccination attitudes.

Women with positive attitudes towards the HPV vaccine were most consistently found to be: born in Australia, were from the quintiles of most and least socio-economic disadvantage, had a past history of abnormal Pap smears, above average cervical screening knowledge, had heard of the HPV vaccine prior to participating in the study and had positive attitudes towards vaccination in general. The model as a whole accounted for 24% of the variance in HPV vaccination attitudes amongst women in this sample.

5.8 SUMMARY OF THE FINDINGS OF PHASE 1

Queensland women who participated in this study had good knowledge of the purpose of the Pap smear and familiarity with the recommended NCSP screening interval; however there was poor knowledge of participants regarding the age range of the eligible population. There was also considerable uncertainty expressed by participants about some risk factors for cervical cancer, especially the role of HPV and sexual behaviours. There was little variation in cervical cancer/screening knowledge with the only differences observed by screening status with underscreened women having lower knowledge compared to more regular screeners. This was confirmed by multivariable analyses in which screening status was found to be an independent predictor of cervical cancer/screening knowledge.

Almost two thirds of women (63%) had heard of HPV. Awareness of HPV was most common amongst women who were born in Australia, had completed post school qualifications, were married, who had an abnormal Pap smear in the past and who had above average knowledge about cervical cancer/screening. There was limited knowledge and high levels of uncertainty amongst participants about HPV. Lower knowledge was evident in older women, women in married and defacto relationships and those with poorer cervical cancer/screening knowledge, women who had not heard of the HPV vaccine and those who had negative attitudes towards HPV vaccination.

A high proportion of participants had heard of the HPV vaccine (over 86%) and the most commonly cited sources of this awareness were mass media. Women with lowest awareness of the HPV vaccine were aged 30 to 39 years and 60 to 69 years, had been born overseas, had never had an abnormal Pap smear, had not heard of HPV and had below average cervical cancer/screening knowledge.

Women had positive attitudes towards HPV vaccination and those with positive attitudes towards the HPV vaccine were most commonly born in Australia, from SES quintiles of highest and lowest disadvantage, had a past history of abnormal Pap smears, above average cervical screening knowledge and had heard of the HPV vaccine prior to participating in the study. Women with positive attitudes to vaccination in general were more consistently found to also have positive HPV vaccination attitudes.

The implications of these findings are discussed further in Chapter 8: Discussion and Chapter 9: Conclusions. The findings of Phase 1 informed Phase 2 of the study which aimed to explore the primary research questions in greater depth. The research design for Phase 2 is described in the next chapter.

Chapter 6: Research Design Phase 2

This chapter describes the design adopted by this research to achieve the aims of Phase 2 of the study. The methodology for Phase 2 of the study is described in Section 6.1; in Section 6.2 the aims of Phase 2 are outlined, and Section 6.3 contains details about how women were recruited for the focus groups. In Section 6.4, the data collection instruments used in the focus groups are described, Section 6.5 provides an outline of how the focus groups were conducted and the timeline for completion; and in Section 6.6, how the data was analysed is discussed.

6.1 METHODOLOGY AND RESEARCH DESIGN

Phase 2 utilised focus groups to gather in-depth information about women's knowledge, awareness and acceptance about cervical cancer prevention and further explore and explain the findings of Phase 1. A qualitative approach was incorporated into this study to produce information rich data and answer questions not suited to the structured format of the telephone survey, particularly those relating to sensitive subjects for example, perceptions about barriers to screening (Liamputtong and Ezzy, 2005).

The Health Belief Model (HBM) was used as the conceptual framework underpinning the study as described in Section 3.2. The HBM was used to inform the topic guide used in focus groups, (Appendix L), and provided overarching themes for data analysis that were defined a priori, and the experiences and perceptions of participants as they related to these themes, were described from focus group transcripts.

6.2 RESEARCH QUESTIONS

The primary aim of the qualitative arm of the study was to ascertain what Queensland women say about cervical cancer, cervical screening, HPV and the HPV vaccine and what they perceive as the most effective methods of communication and health promotion should changes be made to the National Cervical Screening Program (NCSP).

The research questions to be answered by this component were:

- What do Queensland women know about cervical cancer/screening and what are their attitudes towards Pap smears?

- What do Queensland women know about human papillomavirus (HPV) and what are their attitudes towards the cervical cancer/HPV vaccine?
- Where do Queensland women get their health information from and what do they women perceive as the most effective methods of communication and health promotion should changes be made to the NCSP?

Focus groups were conducted to gather in-depth information for Phase 2 of the study and were facilitated by the research student. This method has been adopted by a number of researchers exploring women's attitudes and knowledge about HPV, cervical cancer/ screening and the HPV vaccine from which valuable information has resulted to inform policy decisions and further research (Mays, Sturm and Zimet, 2004; Mays et al., 2000; Olshen et al., 2005; Zimet et al., 2000; Brabin, Roberts and Kitchener, 2007; McClelland and Liamputtong, 2006). Phase 2 built on the first phase of the study as it enabled in-depth exploration of what women thought caused cervical cancer, how serious it was as a condition, their experience of it, whether they perceived they were at risk of it and the purpose of and barriers to Pap smears. It also enabled further exploration of their knowledge of HPV and the HPV vaccine and their attitudes to HPV vaccination.

This study extends previous investigations given it is the first study conducted in the Queensland setting since the implementation of the National Human Papillomavirus Vaccination Program (NHPVP).

Focus groups have also been reported to be useful following the analysis of large-scale quantitative surveys as they facilitate interpretation of the results and add depth to structured survey responses (Stewart and Shamdasani, 1990). They allow the researcher to interact directly with respondents, provide opportunities for the clarification of responses and the opportunity to obtain large and rich amounts of data in the respondent's own words (Stewart and Shamdasani, 1990). They are an effective forum for the discussion of ideas and the exploration of subjective issues, such as attitudes, feelings and beliefs (Dixon, year unknown).

Focus group discussions were conducted in settings nominated by community women to ensure the research was conducted in a setting in which they would be familiar and feel comfortable.

6.3 PARTICIPANTS

The snowball sampling technique was used to recruit women for focus groups with the assistance of service providers and key community women. A priori sampling was used to select participants, that is, participants were chosen according to specific characteristics and structure, although this does not preclude the inclusion of participants with alternative characteristics as the study progresses (Ulin, Robinson and Tolley, 2005). Women aged 20 to 69 years who had not had a hysterectomy were invited to participate in focus groups in metropolitan, regional and remote settings.

Participants were recruited through community organisations and services, including the Queensland Country Women's Association (QCWA), Zonta International, Women's Health Centres and three social groups. The QCWA is a non party political, non sectarian organisation with 274 local branches throughout Queensland that offer a host of activities – such as cookery, dressmaking and public speaking, and friendship and support, not just to members but to the wider community. Zonta International is a global organization of executives and professionals working together to advance the status of women worldwide through service and advocacy and has 47 Clubs throughout Queensland. The social groups were a church group, a book club and a group of co-workers and friends from a metropolitan hairdressing salon. These groups were selected as it was assumed women had existing social networks and would be comfortable participating in a focus group with their peers. It was also assumed women at most risk for cervical cancer were members of these organisations, such as women residing in remote locations and low socio-economic status (SES) areas, women from culturally and linguistically diverse backgrounds, women over 50 years of age and women who were unscreened or underscreened for cervical cancer.

Aboriginal and Torres Strait Islander women are also at increased risk of cervical cancer; however, due to the sensitivity of this topic and respect for the ownership of research conducted in Aboriginal and Torres Strait Islander communities, Aboriginal and Torres Strait Islander organisations were not specifically targeted for the purposes of this study.

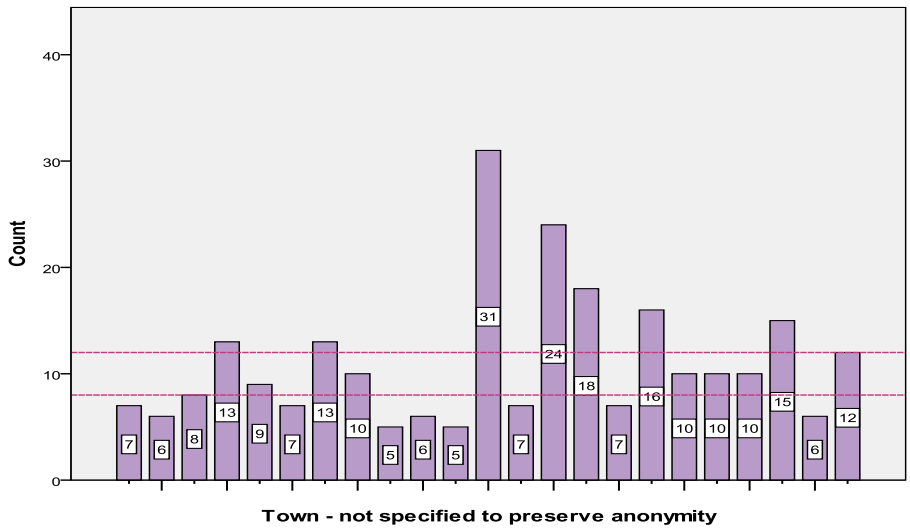

Figure 6.1. Number of Women Participating in Focus Groups Conducted in Queensland, 2009.

Recruitment ceased at the end of the allocated time set for Phase 2 of the study. Twenty three focus groups were held across Queensland between February and December 2009. The number of women participating in the focus groups ranged from five to 31 with the ideal range being eight to 12 women as marked by dotted lines (Figure 6.1). The recruitment information sheet specified women should be aged 20–69 years and have not had a hysterectomy; however women who had had a hysterectomy (number unknown), two women aged 18–20 years and 30 women over 70 years of age arrived ready to participate in the focus groups. The number of focus groups was primarily driven by the need to access women from all localities and the enthusiasm of the organisations involved in participating in the focus groups. No women were excluded as they had presented in good faith and were keen to participate.

Whilst 23 focus groups was a large number of groups to achieve the aims of this study, women's engagement and desire to participate was high and focus groups were conducted wherever interest was indicated within time and cost restrictions.

6.4 FOCUS GROUPS TOOLS

The HBM was used as the organising framework to guide the development of the topic guide for focus group discussions (Rosenstock, 1974; Connor and Norman, 2005; Brewer and Fazekas, 2007; Ulin, Robinson and Tolley, 2005). The topics discussed and their relevance to the research questions of interest and aspects of the HBM are outlined in Table 6.1.

This topic guide was used to guide discussion and was modified during the course of qualitative data collection (Ulin, Robinson and Tolley, 2005; Brewer and Fazekas, 2007). Modifications to the topic guide included the addition of a question about a hypothetical test– '*If there was a test that you could do at home, say a tampon or swab you could insert yourself and send in the mail – do you think women who don't go for Pap smears now might do it?'*, as this emerged in the literature and media about one month after focus groups commenced and was worth exploring as there was no published data about this in the Australian context. The concept of embarrassment as a barrier to having a Pap smear was explored in greater detail than originally intended as it was so frequently raised in the first few focus groups.

A question to explore women's views about sending a letter about changes to the NCSP to women on the Pap Smear Register (PSR) was also added to the topic guide after it was suggested in one of the first groups.

6.5 PROCEDURE AND TIMELINE

6.5.1 Recruitment

The researcher firstly engaged with the Cancer Screening Services Branch Consumer Representative Group to discuss the study and ascertain if the presidents of the QCWA and Zonta International were interested in assisting with recruiting women to participate in the study. This group was consulted at all stages of the process and also participated in a focus group as an educational experience on completion of the focus groups, for their personal information, and to know how the process was conducted. This focus group was not part of this study. The researcher also attended two meetings of Women's Health Centre Managers and provided information about the study and sought their involvement.

These representatives were interested in assisting with the study and disseminated information about it to their organisations and the researcher was contacted by regional representatives and made arrangements with them to hold focus groups. Regular contact was maintained with the organisers and where possible an attempt was made to ascertain the number of women likely to attend each group. It was recommended the ideal size of a group was between eight and 12 women.

Table 6.1 Information Collected to Inform Phase 2

Research Question	HBM CONSTRUCTS	HBM RELATED TO SUBJECT	QUESTION
What do women know about cervical cancer/screening and what are their attitudes towards Pap smears?	Self-efficacy	Women's belief that they are able to influence their own health	What do you think of the following statement: 'Good health is largely a matter of good luck'?
	Perceived susceptibility to disease	Perceived susceptibility to cervical cancer	What do you think causes cancer of the cervix? How common is it?
			Do you think every woman has the same risk of getting cancer of the cervix?
	Perceived seriousness of disease	Perceived seriousness of cervical cancer	If a woman gets cervical cancer, is there a cure? Do you think it would have a big impact on a woman's health?
	Perceived benefits of taking action	Perceived benefits of cervical screening	What do you know about Pap smears? How good are Pap smears at preventing cervical cancer?
	Perceived barriers to action	Perceived barriers to cervical screening	What do you think prevents some women from having Pap smears or putting them off? What do you mean when you say Pap smears are embarrassing? Is it the same embarrassment as say having check-ups when you're pregnant? [1]
	Cues to action	Alternatives that may be more likely to prompt action	Hypothetical - If there was a test that you could do at home, say a tampon or swab you could insert yourself and send in the mail – do you think women who don't go for Pap smears now might do it? [1]
What do Queensland women know about HPV and what are their attitudes towards the cervical cancer/HPV vaccine?	Perceived susceptibility to disease	Perceived susceptibility to HPV infection	What do you know about human papillomavirus or HPV?
	Perceived benefits	Perceived benefits of HPV	What do you know about the new vaccine for preventing cancer of the cervix?
	Cues to action	Information or advice that may trigger one to participate in cervical screening or vaccination, or consent for child to be vaccinated	What do you think would prompt a woman to agree for her daughter to have the vaccine or to have the vaccine herself?
What do they women perceive as the most effective methods of communicating and promoting new information should changes be made to the NCSP	Cues to action	Sources of knowledge that may trigger one to participate in a renewed NCSP.	Where do you get your health information from? The QCSP has developed a number of ways to provide information about HPV and cervical cancer –If there was new information we wanted to provide to women - what do you think is a good way to do this? If the PSR sent a letter to women with information about changes to the NCSP, would this be a good idea? [1]

[1] Added to the topic guide after focus groups commenced

The method chosen to disseminate information and recruit women was guided by the organiser and differed by organisation and group. Information flyers were provided with details about the study and were posted on noticeboards or tabled at meetings for members to consider (Appendix B). A colleague and work related associate who had heard about the study and a group of young women were recruited through 'social networks'.

6.5.2 Process

Some groups were conducted as part of Women's Health Events, such as Pamper Days (a women's health expo where women can have a facial or massage and speakers present or display health information), in conjunction with regular meetings or events, or were held specifically for the purpose of the research project. As a result it was not always possible to know the number of women likely to attend a focus group prior to the event. The venues included QCWA halls, function rooms in hotels or clubs, women's health centres, local halls or function venues, a church and individual homes.

The process for conducting the focus groups was somewhat standard in terms of the format, although protocols differed according to the organisation and the event. When the event was held as part of a formal meeting the researcher was often formally introduced or welcomed at a particular point in the meeting agenda by a senior person. When formal meetings occurred with dinner, focus groups were conducted when formal proceedings had ended or after the meal. At other times, the process was very informal and it was handed over to the researcher to coordinate.

At the start of each focus group, the researcher would introduce herself to women and asked them to read the information sheet (Appendix B) and complete the consent form and a brief questionnaire if they wished to participate (Appendix C; Appendix M).

Once this was completed women's permission was sought to audio-tape the session and the researcher provided a brief overview of her background and the rationale for the study and the process to be followed for the focus groups. She also advised women that no answers or corrections would be made during the focus group but that this would occur in the information session at the end, where answers to the questions and misconceptions or additional queries that arose during the session would be addressed. Women were encouraged to talk about anything they had heard in relation to the questions asked, even if they were not sure if the answer was correct or not, in an attempt to prompt discussion rather than have women feel they were being assessed or examined.

The topic guide was used to guide the flow of the discussion, although at times women would move on to the next question without prompting. The discussion was often informal, particularly in smaller groups and aimed to provide a relaxed atmosphere for women to share their stories and experiences.

At the end of this discussion a brief clarification/education session was provided based on women's responses to the questions asked during the focus group discussions. This session was therefore individualised to each group; however similar topics were covered across all groups and an overview of these topics is provided in Appendix N. This was especially important as women's responses were not challenged during the focus group discussions when incorrect responses were given to ensure accurate information was provided at the end. It was also a good opportunity to provide information for women who were very keen to know the answers to the questions and to respond to the questions women raised during the sessions.

Women participating in focus group discussions were provided with refreshments (appropriate for the time of day in which the focus group discussions were held). At the end of the focus groups they were given a thank-you gift bag, which included a small first aid kit, some beauty products, flower seeds, a candle, a notebook and other miscellaneous items. This gift bag also included some booklets reinforcing the information provided on cervical screening, Pap smears and HPV and a promotional pen "When did you last have a Pap smear" and a make-up mirror about the importance of regular Pap smears.

Women were also asked if they would like to be informed of the outcomes of the focus groups and those who were interested wrote their contact details on a register which was kept separate to the questionnaires and used purely for this purpose.

An observer was present when possible at most focus groups to record observations about the group. These observers were frequently staff from the Queensland Cervical Screening Program (QCSP) or local organisers who were employees of the organisation and preferred to observe rather than participate. These observers kept notes in a journal and were asked to document interesting things they noted about the process, the facilitator or the discussion.

A reflective journal was kept in which the researcher described the context of her own knowledge, experiences and judgements and secondly recorded and acknowledged her experiences and observations during the focus groups (Sharkey, 2001). This was usually

completed within 12 to 24 hours after the group was conducted. An overview of the researcher's personal reflections about the focus groups can be found in Appendix O.

6.5.3 Timeline

Focus groups were conducted between February and December 2009.

6.6 QUALITATIVE DATA ANALYSIS

6.6.1 Data Sources

There were a number of data sources resulting from the focus groups. Firstly, women were asked to complete a brief survey prior to participating in the focus groups to provide some demographic data and assess their previous experience with Pap smears and awareness of HPV and the HPV vaccine. Additional sources of data from the focus groups were transcripts from the audio tapings of focus group discussions, observer notes and notes kept in a personal reflective journal.

6.6.2 Survey Data Analysis

The brief survey data were initially entered into Excel 2007 and analysed by a research assistant. Data was reanalysed using SPSS Version 16 to verify the findings. Descriptive data is presented to provide a brief overview of the participants' characteristics and groupings and was conducted in a similar manner to that described for the computer-assisted telephone interview (CATI) survey. This is presented as counts and percentages with the exception of age, which is also described as mean age as it was normally distributed when a continuous variable.

6.6.3 Analysis of Focus Group Discussions

There were four key stages used to analyse the data from the focus groups as outlined by Hennink (2007), namely:

- Stage 1: Data preparation
- Stage 2: Identifying themes in the data
- Stage 3: Labelling the data by themes
- Stage 4: Using the framework for analysis.

Stage 1: Data Preparation

The statistical software package NVivo version 9 was utilised for the analysis of focus group data. NVivo was used to assist with managing focus group data from multiple sources, was the tool used to code themes in the data and provided a tool for querying the data and developing models (Bazeley, 2007).

The observer notes were transcribed by a research assistant and entered into NVivo. The majority of audio-tape recordings (16) were transcribed verbatim by the researcher with the remainder transcribed by three research assistants. Transcribing the data was a very time consuming process as the audio-tapes were at times difficult to hear as outlined in Section 9.3, and required extensive effort in listening and re-listening to the tapes to capture the data accurately. The researcher reviewed all audiotapes and corresponding transcriptions to clean, label and anonymise the data. Data cleaning was undertaken to ensure there were no errors in the transcripts and that they were accurate and also reflected emotive responses, such as laughter or emphatic tones, for example, *R3: "Ooooh, oh my God!" (gasps)*. Labels were assigned where possible to different speakers to track what individual speakers were saying and identify if one person was dominating the conversation or whether a passage included statements from a number of different women (Hennink, 2007). The transcriptions were also anonymised to remove any names of people, locations, health clinics or hospitals or any identifying information that may compromise the confidentiality of women or the focus groups in which they participated (Hennink, 2007). This was particularly important as a number of focus groups were conducted in small community settings.

Stage 2: Identifying Themes in the Data

Willig (2008), describes four steps in analysing transcripts with the first stage involving immersion in the data by reading and rereading transcripts and recording initial thoughts and observations about the text. The second stage involves the identification of conceptual themes followed by the third stage in which structure is incorporated into the analysis and themes are clustered into natural clusters of concepts (Willig, 2008; Chan, Benner and Brykczynski, 2010). In the fourth stage of analysis a summary table of structured themes is produced with quotations or exemplars that illustrate each theme (Willig, 2008).

Themes are topical markers of various parts of the discussion and can be issues, concepts, influences, explanations, ideas or other topics which mark the focus of the discussion (Hennink, 2007). In this stage of the analysis, the transcripts of each focus group

were read and re-read. The overarching themes in the analysis were identified from the explicit areas of the topic guide and the main constructs of the HBM as described in Section 6.1 to highlight the parts of the discussion devoted to each specific topic. A deductive, semi-structured approach to data analysis was therefore used, whereby the constructs of the HBM provided predetermined overarching themes and the questions underpinning them to structure the analysis (Morgan, 1997).

The process of developing themes began through the identification of themes from the specific issues discussed under each topic by systematically working through a number of focus group transcripts (Bazeley, 2007; Hennink, 2007). This first step in the process resulted in many themes, which were refined through a process of developing, reviewing and building and collapsing themes until key themes were identified (Bazeley, 2007). The process of developing and collapsing themes continued through the analysis until data saturation was reached whereby no new themes were identified from the data (Miles and Huberman, 1994).

Other codes not relevant to the HBM were also generated in this process that related to group dynamics, emotive responses and factors impacting on the quality of data collection and recording, such as background noise, which were noted and are reported in Appendix O (Ulin, Robinson and Tolley, 2005).

Stage 3: Labelling the data by themes

Once a core list of themes were identified and entered into NVivo, the whole data set was indexed against these themes through a systematic process of reading and re-reading the transcripts, examining the content and marking each segment of text with the appropriate theme labels until the whole data set was labelled where appropriate (Hennink, 2007).

Stage 4: Using the framework for analysis

The final stage was the descriptive analysis of the data in which the theme labels were used to identify all segments of the text relating to a specific theme and examining the discussion of that theme across the entire data set (Hennink, 2007). This was done by focusing on one theme a time and was facilitated by the use of NVivo whereby each theme or node could be displayed across all focus groups at once (Bazeley, 2007).

From this process, summary tables of the themes that emerged for each topic where produced including exemplars of what women said that led to these interpretations, which were used to describe the findings (Chapter 7). The final stage of analysis involved the

synthesis of research findings as they relate to the research objectives, which are described in Chapters 8 and 9.

6.6.4 Establishing Rigour

Whilst debate exists about the appropriateness of specific criteria to validate the authenticity of findings in qualitative research (Miles and Huberman, 1994), the researcher has aimed to establish trustworthiness in this findings of this study. The principles described by Liamputtong and Ezzy (2005), for establishing theoretical, procedural, interpretative and evaluative rigour and rigorous reflexivity were used to guide this process.

a) Theoretical rigour relates to the rationale and choice of methods for addressing the research question. The HBM is considered appropriate to explore individuals' knowledge and attitudes towards screening and preventative behaviours as outlined in Section 3.2. Coherence in the presentation of findings and integration with the underlying theoretical framework was also used to demonstrate this (Willig, 2008). Theoretical rigour will also be proven when publication of the findings from focus groups are available for peer review (Liamputtong and Ezzy, 2005).

b) Procedural or methodological rigour in this study is demonstrated by clear documentation of methodological and analytical decisions, which are discussed throughout this methods section and have also been documented during the research process in a reflective journal. This includes situating the sample by describing participants and their life circumstances (Section 7.1) to allow the reader to assess transferability or the relevance and applicability of the findings to other settings (Willig, 2008). An audit trail of analytical decisions was also recorded in a coding journal (Miles and Huberman, 1994). The findings of these focus groups have been presented in multiple settings including a national conference, a national forum of professional peers (Program Managers), and three local meetings of consumers, clinicians and cervical screening experts and positive feedback was received on the process, findings and deductions (Appendix E).

c) Interpretative rigour is reflected by clearly demonstrating how interpretation was achieved and through accurate representation of the events and actions that led to interpretation (Liamputtong and Ezzy, 2005). Direct quotes (exemplars), have been included to provide the reader with insight into how data was interpreted and described and establish trustworthiness in the analytical process. Inter-rater reliability is another method used to demonstrate interpretative rigour; although this is questioned by some

qualitative researchers (Liamputtong and Ezzy, 2005). A colleague, who had been an observer at five focus groups, reviewed a sample of transcripts for the purpose of credibility checking (Willig, 2008). A random sample of three focus group transcripts was selected (by pulling names out of a hat), which were coded separately by hand. The researcher then reviewed the codes assigned to these transcripts and there were high levels of consistency such that the coding framework was considered credible.

The use of mixed methods as in this study also facilitates interpretative rigour as triangulation provides a more complex picture of the phenomenon being studied (Liamputtong and Ezzy, 2005). The qualitative phase in this study was designed to explore the findings of the quantitative survey and as the methods complement each other, should also contribute to trustworthiness if there is consistency between the findings.

d) Evaluative rigour relates to the ethical and political aspects of the study and relate to procedural processes such as obtaining ethical approval and consideration of the political and social consequences of the research (Liamputtong and Ezzy, 2005). The ethical processes used for this research are described in Section 3.3.

There were no anticipated political consequences of this research; however there was a potentially sensitive social issue that emerged during the focus groups that needed to be managed carefully. As discussed in the literature review, cervical cancer and its association with a sexually transmitted disease has not been widely promoted in the Australian setting until the introduction of the HPV vaccine. Women often disclosed in the focus groups that they had either had cervical cancer or abnormal Pap smears in the past. When HPV was then discussed as being the cause of cervical cancer, this potentially placed these women in a difficult and shameful situation given the stigma associated with sexually transmitted infections (STIs).

This was actively managed by de-stigmatising HPV and describing it as 'the common cold of sexual activity', (Hammond, 2006) and women did not appear to suffer any distress resulting from the discussions. This also highlighted, the value of using established social networks for this type of research as these women knew each other very well and frequently discussed quite intimate details with each other during the focus groups.

e) The final aspect of establishing rigour is reflexivity which acknowledges the researcher is part of the setting, context and culture they are trying to understand and analyse and

therefore has to be honest about their role (Liamputtong and Ezzy, 2005). The researcher's role and experience is described in Appendix P.

The key findings relevant to the aims of Phase 2 of this study as described in Section 6.2 are described in the next chapter, 'What Queensland Women Say about Cervical Cancer/Screening, HPV and the HPV Vaccine'.

Chapter 7: What Queensland Women Say about Cervical Cancer, Pap Smears, HPV and the HPV Vaccine

This chapter describes the findings from Phase 2, the qualitative component of this study. The research questions to be addressed by this phase of the study are described in Section 6.2.

In Section 7.1, the characteristics of women attending the focus groups are described including their screening history and awareness of human papillomavirus (HPV) and the HPV vaccine. The findings from the focus groups are then described in the following sections: self-efficacy in Section 7.2, perceived susceptibility to cervical cancer in Section 7.3, perceived seriousness of cervical cancer in Section 7.4, benefits of screening in Section 7.5 and barriers and enablers in Section 7.6. Women's perceptions about their susceptibility to HPV are described in Section 7.7 followed by benefits of HPV vaccination in Section 7.8. Cues to action including where women obtain health information and their recommendations for information dissemination are described in Section 7.9 with the findings of the focus groups summarised in Section 7.10.

7.1 CHARACTERISTICS OF WOMEN ATTENDING FOCUS GROUPS

Overall, 256 women consented to participate in the focus groups. The average age of participants was 55 years (SD 14.89; range 18 to 88 years) with one third of women in the 60–69 year age group (Table 7.1). Focus groups were held in the following locations, some of which are not named specifically to maintain women's confidentiality as these were small communities: Fraser Coast, Townsville, Gympie, Atherton, Goodna, Gladstone, Laidley, regional areas around Rockhampton, Childers (and surrounding areas), the Gold Coast, Morayfield, Caboolture, Mt Isa, a regional town near Roma, Roma, Charters Towers, two inner Brisbane suburbs and Redland Bay (Figure 7.1).

The majority of women (41%) were recruited through the Queensland Country Women's Association (QCWA), were from inner regional areas (45%), were married (63%) and 88% had children (Table 7.1).

Table 7.1. Characteristics of Women Attending Focus Groups in Queensland, 2009

Socio-demographic Characteristics	N=256[1]	%
Recruitment (n=255)		
QCWA	104	40.8
WHC	70	27.5
ZONTA	62	24.3
Social	19	7.5
Age (n=249)		
< 20 years	2	0.8
20–29	16	6.4
30–39	28	11.2
40–49	38	15.3
50–59	49	19.7
60–69	83	33.3
70–79	28	11.2
80–89	5	2.0
Locality (n=255)		
remote, very remote	29	11.4
outer regional	69	27.1
inner regional	115	45.1
major cities	42	16.5
Country of Birth (n=251)		
UK	13	5.2
NZ & Oceania	4	1.6
Other	11	4.4
Australia	220	88.7
Aboriginal or Torres Strait Islander (n=218[2])		
Yes	6	2.8
No	212	97.2
Marital status (n=250)		
never married	15	6.0
married	158	63.2
defacto	25	10.0
separated/divorced/widowed	52	20.8
Children (n=249)		
no	30	12.0
yes	219	88.0
Schooling (n=248)		
still at school	1	0.4
less than year 10	42	16.9
year 10 or equiv	76	30.6
greater than year 10	128	51.6
don't know/not stated	1	0.4
Post school qualifications (n = 234)		
yes	131	56.0
no	103	44.0
Post school qualifications – stated (n = 131)		
diploma or certificate	68	51.9
bachelor degree or higher	47	35.9
don't know/ not stated	16	12.2

1 Missing data for some questions; denoted by (n= x)

2Excludes those born overseas

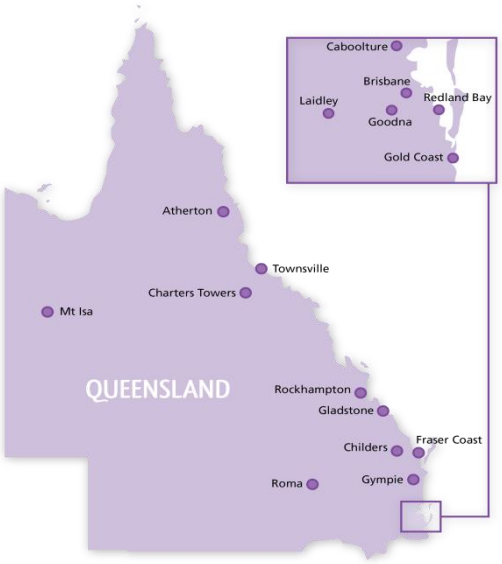

Figure 7.1. Locations of Focus Groups in Queensland, 2009

Table 7.2. Screening History of Women Attending Focus Groups in Queensland, 2009

Screening history	**N**	**%**
Ever had a Pap smear (n = 245)		
yes	253	95.5
no	12	4.5
Number of times had Pap smear (n = 245)		
never	12	4.9
once	11	4.5
twice	5	2.0
3–5 times	22	9.0
6–10 times	55	22.4
11–20 times	93	38.0
more than 20 times	27	11.0
don't know / can't remember	20	8.2
Last Pap smear (n = 234) [a]		
< 1 year ago	71	30.3
1 year to < 2 years ago	94	40.2
2 years to < 3 years ago	23	9.8
3 years to < 5 years ago	10	4.3
5 or more years ago	27	11.5
don't know	9	3.8
Usual time between Pap smears (n = 225) [a]		
1 year or less	7	3.1
1 year	27	12.0
2 years	158	70.2
3 years	10	4.4
4 years	2	0.9
5+ years	8	3.6
don't know/refused	13	5.8
Heard of HPV (n=247)		
Yes	149	60.3
No, don’t know	98	39.7
Heard of HPV vaccine (n=247)		
Yes	222	89.9
No, don’t know	25	10.1

[a] Excludes women who had never or had only had one Pap smear when asked the number of times they had had a Pap smear.

Most women attending the focus groups had had at least one Pap smear (95%) and most had had between 11 and 20 in their lifetime. Eighty percent of women said their last Pap smear was less than three years previously and 70% reported they had a Pap smear every two years. Just over 60% of women attending the focus groups had heard of HPV and 90% had heard of the vaccine prior to participating in the study (Table 7.2).

In the following sections, the findings of the focus groups are discussed and as described in Section 6.6.2, the constructs of the Health Belief Model (HBM) provide predetermined overarching themes with women's responses relevant to these themes described. Key exemplars that reflect women's responses and how they were clustered under these themes are described in Section 6.6.2.

Each focus group commenced with a general discussion about health and the role of luck, which relates to self-efficacy in the HBM (Rosenstock, 1974). This enabled women to talk about a neutral topic and ease them into the process rather than commencing with a topic they may be less familiar or comfortable with, such as risk factors for cancer. It also provided a sense of whether women in the groups considered they had some control over their own health.

7.2 SELF-EFFICACY

'What do you think of the following statement: "Good health is largely a matter of good luck?'

When first asked about the statement, 'good health is largely a matter of good luck', some women opposed it quite strongly, *"Definitely not, no!"* Most women did not consider health was related to luck and they talked about the things within their internal locus of control - self management, and those they could not control - external factors (Table 7.3). Good self management included choices about diet, exercise, smoking etc and having regular health checks. Some women did talk about the importance of being aware of your own body but lifestyle factors were the main focus of discussion.

When the role of luck was discussed in relation to health, this largely related to external factors, such as acute events like accidents or women's reflections about people they knew, that refuted the amount of influence an individual may have on their own health.

Table 7.3. Themes Related to Self-Efficacy from Focus Groups Conducted with Queensland Women, 2009

SELF EFFICACY	
Themes	***Exemplars***
Self Management	
• **Health protection** • **Self awareness** • **Lifestyle**	• *FG2: When services are available we should be using them shouldn't we?* • *FG16: Yeah, it's the way you look after yourself – as long as you get everything done.* • *FG2: I have a feeling that I won't get it – I just have this feeling mmm…* • *FG6: Sometimes you rely on your gut feeling too that something's wrong, you know something is nagging – I said what's going on here – I'd rather have peace of mind* • *FG10: I don't believe that good health is good luck. It's how you look after your body. What you put into your body - It's your lifestyle, you are what you eat.* • *FG19: I would go along with lifestyle, whether you exercise, what you eat, how you sleep, stress* • *FG22: Because it's up to you - weight and smoking and drinking and all that*
External Factors	
• **Luck**	• *FG9: I think luck has got a lot to do with it as well because you can't choose your disease can you?* • *FG15: Well sometimes bad luck can lead to acute events, which can lead to bigger and worse things - car accidents. You know events like that, you have literally no control over, can lead to a coma or morbidities later down the track.* • *FG22: I was initially going to say no as well, (inaudible), but you are right I know too many people who don't smoke, never drink and then have died at 40 without a say, I think yeah you can say it is bad luck.*
• **Family history / genetics**	• *FG14: Well she never made the choice to have diabetes because she always she looked after her health, and ate and did it right, and that's the genes – that family's very much like that isn't it …* • *Fg22: But then also some people get, you know it's either hereditary or they get different cancers and they are perfectly fine and to me that is just rotten luck you know. People who have lived a good life and all that sort of thing...*
• **Environment**	• *FG10: It's your environment too. Being in X with the air pollution hasn't – there is a lot of sickness up there.*

Women generally considered they could control some factors of their health but other factors, such as genetic factors and family history, environmental factors and acute events, were beyond their control and these latter factors were more often associated with luck.

These themes were similar across all groups and discussion of this topic was fairly brief as women were generally consistent in their beliefs about good health, the role of self management and that a person had control over the choices they made that influenced their health, except when genetic factors and acute events were responsible.

After discussing this statement we moved on to specific topics related to the main research questions, the first of which was, *'What do Queensland women know about cervical cancer/screening and what are their attitudes towards Pap smears?'* The key themes that described women's responses to this question are discussed in the following section.

7.3 PERCEIVED SUSCEPTIBILITY TO CERVICAL CANCER

To determine women's perceived susceptibility to cervical cancer, women were asked what they thought caused cervical cancer and increased a woman's risk for developing cervical cancer.

7.3.1 Causes of Cervical Cancer

Uncertainty - But I have no idea!

The most common response from women's comments at the beginning of this discussion was uncertainty, which was evident in 12 of the 23 focus groups (Table 7.4). There were two sub-themes within uncertainty, the first was 'don't know', and the second was 'haven't thought about it'. Women said they did not know what the cause of cervical cancer was and this was sometimes discussed within the notion that no-one knew the cause of cancer ("*they don't know")*. There were also some women who believed it was information not given to them, that is, they were not told about it (Table 7.4).

When women discussed causes, trigger factors, a relationship with sex, lifestyle factors, infection, other gynaecological problems and family history were described.

Triggers - You just need something to trigger it off

Women talked about triggers in relation to cancer cells, which was not always associated with HPV and for these women there was the notion that the abnormal cells were present in everyone's bodies but something makes the cells mutate, which some women attributed to sexual activity. These women suggested in their discussion of trigger factors that they had no control over the development of cancer (Table 7.4).

Sexual encounters

Another theme was that women thought there was a link between cervical cancer and sexual activity but there was uncertainty as to what it was about these sexual encounters that led to cancer. There were aspects described that related firstly to sexual activity as a physical act, and secondly to factors that increased the risk of infection, such as 'playing around' or multiple partners. Sexual activity as a physical act was described in terms of the mechanics of sex and was sometimes linked to the trigger concept, although some women thought sexual activity was a protective factor. Infection and behaviours that increased women's risk of acquiring an infection were also described. Having multiple partners was frequently raised as something that caused cervical cancer, although at times women debated this, especially when they reflected on the stories they had heard from women who had developed cervical

cancer. There was also some uncertainly about women who had never been sexually active and whether they were at risk.

Infection - the virus

The theme that there was an infective agent was evident in most groups and human papillomavirus (HPV), was identified but more often it was referred to as 'the virus' or sometimes 'the wart virus'. Whilst HPV was often mentioned, it was common for women to say this was all they knew. Women also referred to HPV as a trigger factor for cervical cancer and although often sure about where it came from, thought the activity of sex or something to do with the male triggered it (Table 7.4).

There were only five focus groups where the 'virus' was not mentioned as a cause, although in many of the groups not all women had heard of this which led to the theme '*virus, what virus?'*. In addition to HPV, other STIs and broad terms, such as 'disease', were also raised as possible causes for cervical cancer (Table 7.4).

Lifestyle factors, other gynaecological issues and all in the family

Lifestyle factors were also discussed and included hygiene and personal cleanliness, stress, environmental factors and smoking. There was some debate about smoking as some women did not think it had any relationship with cervical cancer and thought it was mainly a risk for respiratory problems. Some women referred to keeping your immune system healthy and associated a weak immune system and stress with cervical cancer.

The other group of causes women raised were related to other gynaecological conditions or issues, such as endometriosis, hormones and childbirth. Genetic predisposition or family history was another common theme discussed, although at times women seemed unsure about this. On occasion they referred to breast cancer or cancer in general and the role of genetics and family history and questioned if cervical cancer ran in families, although some women gave examples to support why they believed a familial link was possible (Table 7.4).

Women's beliefs about the possible causes of cervical cancer were common across all groups with the exception of a small group of five older women who were all uncertain about what caused cervical cancer and had not heard of HPV.

Table 7.4. Perceived Susceptibility to Cervical Cancer (Causes) from Focus Groups Conducted with Queensland Women, 2009

PERCEIVED SUSCEPTIBILITY - CAUSES OF CERVICAL CANCER	
Themes	***Exemplars***
Uncertainty	
• **Don't know**	• *FG17: No, I don't know what happened with me – out of the blue*
	• *FG13: They don't tell you! They don't explain it to you or why you...*
• **Not thought about**	• *FG5: It's very strange isn't it because we know so much about breast cancer and checking your breasts and we know we have to have a Pap smear every two years but you don't delve any deeper and find out about it.*
Triggers	• *FG13: I'm assuming from what I know of cancer that some people will get it just because their own cells will mutate, but there will be some mutation or change that will induce the cancer, the same as breast cancer has multiple causes–*
	• *FG3: Yes but what if you already have the cancer cells in your body and you just need something to trigger it off?*
Sexual encounters	• *FG7: Yes but can I ask a question, people, single ladies, who don't have sex, I mean, you know what I mean. I've got a cousin, who's my age, who's never been married and has never had sex. Can they get cancer?*
• **Sexual activity**	• *FG3: Could it have anything to do with say ... sexual partners that are very aggressive?*
	• *FG18: Well I thought after you were sexually active then you could get it, not necessarily via sex but I thought once you were sexually active, then the virus could develop in your body by having sex.*
	• *FG6: Is that sleeping around because it increases your exposure to potential dangers or is it the physical activity of a lot of sex?*
• **Playing around**	• *FG1: I had a lady at work that I didn't disagree with it but she said that she'd been told cervical cancer came from having multiple partners and she's only had one partner and yet she's had cervical cancer.*
	• *FG10: I knew you got a lot of things from playing around with other people but I didn't know that's what you got from it.*
	• *FG3: I don't think so. No, I've had multiples of multiples and I don't –*
Infection	
• **The Virus**	• *FG8: It's one of the cancers caused by viruses*
	• *FG13: But I don't know if that's the only ... I have a belief that it's a mutation of the virus that becomes the cancer but I don't know if there was other ways of getting the cancer.*
• **Virus, what virus?**	• *FG18: I was going to say "what in the?" what is that?*
• **Other**	• *FG21: Other, I mean, diseases maybe*
Lifestyle	• *FG5: Not cleaning yourself properly I suppose*
	• *FG11: I heard years ago that women can get it from men but it depends on the kind of work men do – that would have to be 20–25 years ago...yeah, type of work can pass it on - I don't know if that's right or not – I just heard it.*
	• *FG12: I know because I was a smoker and when I went through it they kept telling me to give up smoking because it does not help ...*
Other gynaecological issues	• *FG1: Possibly contraception, as in IUDs, I don't know the name – (Mirena – from another participant) - Mirenas, thank you*
	• *FG21: A lot of young girls now, my daughter's got polycystic ovaries ...what about endometriosis – does that have similar?*
	• *FG19: I thought cervical cancer - childbirth had a lot to do with it*
All in the family	• *FG21: I think there is - my mother-in-law, who I didn't know, she died of cervical cancer – her eldest daughter has sight of it, another one – she had it too – I think it might be hereditary*

7.3.2 Risks of Cervical Cancer

Women were then asked about if they thought there was anything that may increase a women's risk of getting cervical cancer. Whilst there was some overlap with the previous topic, this topic aimed to determine whether women perceived certain behaviours placed them at greater or less risk for cervical cancer. The main themes relating to risk factors are outlined in Table 7.5.

There were similar responses to those identified as causes of cervical cancer, such as infection with 'the virus' (HPV), an association with sex and lifestyle factors; however, risks were assigned to categories within women's internal and external locus of control. Another theme identified from these discussions was 'assumptions' as women frequently talked about the beliefs or behaviours of others, particularly young women.

External locus of control

'Nothing' was an external locus of control theme as some women felt everyone was at risk and there were no factors that placed one woman at more risk than another. Additional external locus of control factors related to age, family history and cultural issues. Many variations were discussed about who was at most risk. Although age was identified as a risk factor, there was uncertainty about this and women debated whether it was a disease of older women, younger women or that age was irrelevant (Table 7.5). However there was concern expressed about young women, which was related to women's assumptions about young women's sexual behaviours as described below and the target age for the vaccine.

Cultural issues were also seen as a factor that may increase a woman's risk for developing cervical cancer and this was themed within external locus of control, as women talked about these issues as factors women did not necessarily have control of (Table 7.5).

Internal locus of control

Internal locus of control factors related to behaviours women raised that they thought placed some women at greater risk of cervical cancer than others, such as lifestyle factors, early sexual debut, multiple partners and unsafe sexual practices. There was also mention of protective behaviours women could engage in, such as safer sexual practices and cervical screening. Lifestyle factors not associated with sexual activity were infrequently raised and included factors such as diet and smoking.

Table 7.5. Perceived Susceptibility to Cervical Cancer (Risks) from Focus Groups Conducted with Queensland Women, 2009

PERCEIVED SUSCEPTIBILITY (RISKS FOR CERVICAL CANCER)	
Themes	***Exemplars***
External locus of control	
• **Nothing**	• *FG13: My view was that there was no prevention other than ...the immunisation but beyond that I didn't have a sense of a lifestyle factor that could prevent it or anything... some people being more prone than the other.*
	• *FG13: I'm not sure, it's just your number comes up and I'm not sure, um I have no thoughts as to why it's there or why some are more at risk.*
• **Age**	• *FG17: Yeah, I wouldn't think age would make much difference*
	• *FG10: I wonder though if say by your 40's, 50's or so when our bodies have less resistance to a lot of things*
	• *FG17: Why else are they giving the young children now, the vaccine?*
	• *FG4: I think probably as teenagers ... thirteen, fourteen, I think it starts really young*
• **Family history / genetics**	• *FG10: I tend to think along the lines of HPV and then the genetic, very much genetically based*
	• *FG14: So obviously that group is more susceptible towards, to whatever so that comes back to the genes*
• **Cultural issues**	• *FG9: And if you are Aboriginal/Islander you are high risk. (Facilitator - Do you have any understanding as to why that might be?) Yeah, the shame factor – a lot of our mob won't go and get their cervix looked at ...*
	• *FG15: I'm just thinking of [developing country] where women ...30% of the female population ... has HIV. They don't know about condoms, they don't know about preventative measures, simply because it's against their religion. So that may have an impact. 'Cause I mean also there is, I'm pretty sure that it is a fact, that uncircumcised males are more likely to carry the virus and pass it on to their partner or partners, than circumcised men.*
Internal locus of control	
• **Lifestyle factors**	• *FG18: Diets is another thing, I mean certain diets, some people don't get, I mean this is generalisation from what I've read about, I mean anything that's around general cancers like that you know.*
	• *FG15: I think smoking makes all cancers more prevalent. So I suppose yes.*
• **Risky business**	• *FG14: I think I heard that the earlier a female engages in sex the higher the rate she has of having cervical cancer. Now I'm not saying that that's correct, that's what I remember and I probably remembered that because I have a teenage daughter and it gave me a reason to say don't!*
	• *FG10: It is more likely if you've had multiple partners or your partner has had multiple partners.*
	• *FG9: That's what's the 'girls of the night' have to do, don't they? They regularly have to get checked.*
• **Health protection**	• *FG9: So then I think you are more at risk with more partners and then I think if people want to lead, you know, activities like that then I still think there needs to be more preventative measures so if you want to have multiples partners as such, if you are not on top of your screening and those sorts of things then you can't really cry at the end of the day if you happen to end up with cervical cancer. It's like well, that's what you can do so for those people that are ignorant then that's a consequence.*
	• *FG13: Well I would have thought so because I always just assumed that it was from the virus so if you have protected sex you are reducing your risk*
	• *FG15: Isn't it a risk that some women simply don't see the need to have Pap smears?*
Assumptions	• *FG18: Well you know, not like the young kids, like they're at it like stoats aren't they!*
	• *FG10: I hear in country areas that people are often more sexually active because as one person once said to me "there is nothing better to do in the town"*

There were some sexual behaviours that women believed increased the risks of getting cervical cancer, although at times these risks were debated such as early sexual debut (Table 7.5). Having multiple partners was frequently referred to and sex work was identified as a risky occupation.

There were also protective behaviours, such as using condoms, which women felt decreased the risk of developing cervical cancer and Pap smears were also discussed within this context. Some women believed condoms would protect against HPV and cervical cancer and also talked about how not participating in screening could increase the risk of developing cervical cancer.

Assumptions - They're at it like stoats aren't they!

The making of assumptions about others' behaviour, particularly young women, was identified in many focus group discussions. This most likely reflected the older age profile of women in the focus groups whose average age was 55 years. There was a perception that young women were more sexually active than women in previous generations. At times words like 'promiscuity' were used - but this was rare and women often used non-judgemental terms, just as often, such as referring to sex workers as 'girls of the night'.

There were similar themes including assumptions identified across all focus groups with the exception of three groups, one which was a young women's group, where no assumptions were made about young women. There was increasing discussion and debate amongst women during this topic as women became more engaged in the focus group process.

7.4 PERCEIVED SERIOUSNESS OF CERVICAL CANCER

When asked *'If a woman gets cervical cancer, is there a cure or do you think it would have a big impact on a woman's health?'*, women talked about the impact of cervical cancer, discussed their personal experience with it or lack of awareness and spoke about how it was rarely discussed.

Life threatening

Women perceived that cervical cancer was extremely serious. It was very sad at one of the groups when a number of women attending left a little early to attend the funeral for one of their members who had died recently from cervical cancer. Cervical cancer was described

as a disease that had serious and negative consequences, and two themes described this, namely, fatalism and early detection.

Women with a fatalistic view of cervical cancer did not believe it was treatable or that Pap smears could detect it early enough. More commonly though women talked about the importance of early detection and believed cervical cancer could be detected early and treated. Women discussed different treatment options that their friends or relatives had had, such as laser treatment, hysterectomy, radiotherapy and how these women lived many years after treatment. The Pap smear was frequently raised as an early detection method that was important in reducing the impact of cervical cancer especially as women often did not have symptoms in the early stages of the disease. Although a few women referred to detecting precancerous changes, Pap smears were primarily viewed as a method for the early detection of cervical cancer and it was rarely discussed as a way to prevent cervical cancer in this context.

Within this discussion, women frequently talked about how they did not know of anyone who had had cervical cancer. The themes 'personal experience' and 'closet cancer' were used to describe women's experience with cervical cancer and community awareness of this disease. Women frequently spoke of how cervical cancer was not talked about very often and they were not highly aware of the disease or of women who had had cervical cancer (Table 7.6).

Personal experience

There were a number of women in the focus groups who knew friends or relatives with cervical cancer and two women talked about their own personal experiences with cervical cancer. Other women disclosed they had had some personal experience with cervical cancer through their own experiences or from friends, family or through extended networks. At times it seemed some women may have confused cervical abnormalities with cervical cancer per se when recounting these experiences due to the treatment they described, such as laser treatment.

Closet Cancer - I can't see women out there with t-shirts on you know

Secrecy was also discussed and the notion of not talking about 'down there' and terms, such as 'hush, hush' and 'taboos', were raised. This was linked to stigma and the association with sexual activity and how others may make assumptions about you if you disclosed having cervical cancer.

Table 7.6. Perceived Seriousness of Cervical Cancer from Focus Groups Conducted with Queensland Women, 2009

PERCEIVED SERIOUSNESS (CONSEQUENCES OF CERVICAL CANCER)	
Themes	***Exemplars***
Life threatening	• *FG10: Yes, people don't have any signs at all and then by the time they do start to have symptoms, bleeding, pain, whatever …. of course, it is too late and it is already spreading or it's picked up its swag and then traced back.*
	• *FG11: That's what they say – if you get it early enough it can be cured but most times you don't get it early enough – I've heard not many women survive it.*
• **Fatalism**	• *FG14: If I had a choice I'd choose breast cancer because you can get rid of that.*
	• *FG7: It's a bit hard to check though, like even in Pap smears they don't always pick it up until late.*
• **Early detection**	• *FG18: Well see, there is cancer and there is abnormal cells isn't there? So the abnormal cells that are pre-cancerous, they just do those cone biopsies where they just, you know, whatever they do, burn it out or whatever, and that removes the damaged cells and that's as far as they go. But if it's not abnormal cells, if it's later on - then it is cancer of the cervix.*
	• *FG13: But my understanding is that if you detect it early then the treatments are pretty effective.*
	• *FG10: But it is very quiet because there is no pain and it just quietly goes about its disaster and very often, it's too late which is why there is so much importance on keeping up with your Pap smears.*
Personal experience	
• Close to home	• *FG17: Well as I was telling x before , I just went out one day to a function and when I came home I noticed something on my underwear, so the next day straight to the doctor to find out what was happening and he sent me straight to the hospital and the next week I was in hospital having my operation.*
	• *FG1: Yes - both my grandmothers died from cervical cancer before I sort of knew them.*
• **A friend of a friend**	• *FG16: My friend in [x], um, her girlfriend's just been diagnosed it and she's devastated. I think they got it too late – I don't ask questions.*
	• *FG11: It can kill you can't it? "Cause I know a lady died of cervical cancer less than a year ago and she was 80.*
Closet cancer	
• **Secrecy**	• *FG21: No, I'm totally naive because I've had no connections – know nobody...*
	• *FG17: No, I don't recall hearing anyone talking about cervical cancer at all*
	• *FG13: And I just think that, I think because you talk about 'down there' as well I think if someone has it they are not as willing to talk about it because there still are a lot of taboos about certain parts of your body.*
• **Stigma**	• *FG18: All the things about breast cancer – there's groups ... people making breast cancer quilts and motor cycle rides and walks and dragon boating - I can't see women out there with t-shirts on - "I've had cervical cancer" you know? It's not the sort of thing that's going to be bandied about is it?*
	• *FG19: I think people think it might portray that you might be loose.*
	• *FG8: Because of stigma, the possible association with the virus.*
• **Pinked out**	• *FG17: There's not enough discussion about it - it's there, it's there but they're not talking about it because some of the other cancers are overshadowing it.*
	• *FG10: Well, breast cancer is everywhere isn't it.*
Talking about my generation	• *FG10: You never heard about all of these in our days when we were young.*
	• *FG23: Within my age group they're only just starting to discuss it amongst each other and anyone older, no, it's something you don't talk about it. And I think you need to because a lot of them are saying 'no, once I've stopped having children end of story'.*

It was also interesting that women perceived breast cancer to be much more socially acceptable to discuss and at times referred to the overexposure of breast cancer, which was termed 'pinked out'.

Talking about my generation

Within this context, women's uncertainty about whether it was as prevalent as breast cancer was also apparent. Older women in particular talked about how such issues were not readily discussed when they were growing up, although they felt things were changing and it was becoming more acceptable to discuss cervical cancer in the current environment where breast and prostate cancer were commonly talked about.

There were similar themes identified across all focus groups with debate and discussion about treatment and early detection. This was at times a somewhat sad and reflective topic within the focus groups as women reflected on family and friends who had died from cervical cancer or recounted their own experiences.

7.5 PERCEIVED BENEFITS OF CERVICAL SCREENING

To determine the perceived benefits of screening, women were asked what they knew about Pap smears in relation to the recommended interval between Pap smears, the age women should commence and cease screening, the purpose of the Pap smear, what an abnormal Pap smear meant and how good they considered the test was at preventing cervical cancer. The exploration of these aspects of cervical screening provided insight into which women were thought to benefit most from cervical screening as well as the benefits associated with Pap smears. Discussion in this topic related to the current National Cervical Screening Program (NCSP) recommendations, beliefs about the purpose and accuracy of Pap smears and women's attitudes towards the test itself (Table 7.7).

NCSP Recommendations

When asked about the recommended interval between Pap smears, women's knowledge was high as they generally believed that the current recommendation was to have a Pap smear every two years unless there were abnormalities detected; however family history was raised as some women thought this increased women's susceptibility to cervical cancer and subsequently thought these women should have more frequent screening. In all groups the commencement of screening was rarely linked with age, although some women had heard they could stop having Pap smears at 70 years of age as they had been advised by their provider or received a letter from the Pap Smear Register (PSR). Women did not mention

that Pap smears could stop at 70 years of age if the woman had had two negative results in the previous five years. Some women disputed that it was safe to cease screening at 70 years of age and felt age was not relevant and that women were entitled to continue having Pap smears irrespective of their age as they considered them beneficial.

It was commonly believed that it was recommended for women to start screening when they became sexually active (sexual debut). There was discussion and debate about this though and on a few occasions women, although believing sexual debut was the recommended time to start screening, worried about girls having to have a Pap smear so young - '*those poor young things'*. Women strongly perceived Pap smears were beneficial for young women given they perceived them to be at risk based on the assumptions they expressed about the sexual practices of younger generations. Other concepts raised about screening eligibility, that were related to sex, were uncertainty about whether women who had never been sexually active would benefit from screening and if Pap smears could stop when women were no longer sexually active. The HPV vaccine was also discussed within the context of starting Pap smears and some women thought both primary and secondary prevention should commence simultaneously. Women were also asked whether Pap smears were still necessary after vaccination and many women believed they were, although some women were concerned young women were not aware that they still needed to have Pap smears as highlighted in Table 7.7.

There were other beliefs, including the belief that screening should commence at menses or stop at menopause, or when starting the Pill as this had been a number of women's experience. There was also discussion about the need for Pap smears after a woman had had a hysterectomy and women gave differing views and accounts of their beliefs about this and what they had been told.

Purpose

When women were asked *'What do you think a Pap smear is a test for?'* women talked about abnormal cells, changes, irregularities and cancer cells. There was some uncertainty apparent and some women used very broad terms or terms associated with a pelvic examination such as *'...to see if you've got any lumps...'*

When asked about efficacy, it became clear the concept of the Pap smear as a preventative test was poorly understood. When asked '*How good do you think Pap smears are at preventing cervical cancer?'* some women were adamant they did not prevent cervical

cancer (Table 7.7). It appeared that many women's understanding of the benefits of Pap smears was early detection and from this it appeared they understood abnormal cells to primarily be cancerous cells rather than precancerous changes in the cells. The notion of the Pap smear being for early detection rather than prevention was raised in 16 of the 23 groups. There was very little mention about precancerous changes, although uncertainty was evident and often women were seeking clarification even when they had been treated previously for abnormalities.

Trust

Women overall were confident in and trusted the Pap smear as a method for detecting early changes and cervical cancer – '*Saved my life, fair dinkum'!* Women also talked about the benefit of the Pap smear in the context that cervical cancer was a 'silent cancer' that showed no symptoms until it was quite advanced. There were some women though, who were uncertain or did not think the Pap smear was able to detect cancer early and there were concerns raised about the time it offered protection for and whether cancer could develop before their next test in two years time. It was clear from these discussions that women knew there were limitations of the Pap smear and did not perceive it to be perfect. Some women spoke of shortfalls of the Pap smear which related to false readings, having to return for a repeat test if they weren't 'done right' and two women in different focus groups referred to a laboratory issue that occurred a decade earlier (Table 7.7).

During discussions about the accuracy of the Pap smear many women spoke of how they were offered an 'extra' test (liquid-based cytology). Women had this test on their provider's recommendation because they were told it improved the accuracy of the Pap smear. They rarely seemed to know what this test was and often did not know what it was called or why you had to pay for it if it was a better test. There was some concern raised in some focus groups, firstly as some women had not heard of it before and secondly, as others thought it was inequitable that not all women could afford this test and they felt it should be available for all women if it was more accurate.

Compliance

Another theme identified during this discussion was compliance. Women talked about how they little they knew about Pap smears despite having had many in the past and attributed this to 'doing as they were told' (Table 7.7).

Table 7.7. Perceived Benefits of Cervical Screening from Focus Groups Conducted in Queensland, 2009.

PERCEIVED BENEFITS OF CERVICAL SCREENING	
Themes	***Exemplars***
NCSP Recommendations	
• **Family history**	• *FG5: If there's something in the family – they'll say come every 12 months.*
• **Age**	• *FG19: When you're too old you don't want to do it [cease screening].*
	• *FG2: When you're say 70, they said 'well, you don't need it' - I said 'well I know people were 80 who've got cancer, so I'm staying every 2 years.'*
	• *FG20: We're not important when we're over 70.*
• **Related to sex**	• *FG22: Well why do they say have Pap smears when you become sexually active?*
	• *FG1: I was just thinking those poor young things – having to go through that [Pap smears]*
	• *FG12: I know my girlfriend's never had a Pap smear 'cause she's never had sex and I've always said to her I think you should still go*
	• *FG21: We're just wondering if you're not sexually active – when you stop having sex can you stop having them?*
• **Vaccination**	• *FG19: I think with the virus injection now and I mean and you're only 12 or 13 - it must be going to come in line with that.*
	• *FG2: I worry about with this wonderful new vaccination – the younger women are going to say,' I've been vaccinated, I won't bother going'*
	• *FG18: Like some people will go and have the injection and think 'I'm fine now for the rest of my life', but you have to know whether that...*
• **Other**	• *FG13: When I went to uni ..., I was seeking contraception and she gave me a Pap smear and she told me I had to have one every year so I did.*
	• *FG22: But if you've had the hysterectomy then you don't have a Pap smear do you?*
	• *FG2: I thought when you finished your menses, then you could stop.*
Purpose	• *FG16: I wouldn't have a clue!*
	• *FG8: To see if the virus is there or change in the structure of the cells in the lining.*
	• *FG16: I didn't think – I don't know – maybe sexually transmitted infections – I thought it was for everything – I don't know – cancer.*
	• *FG20: No ... maybe to see if you've got any lumps and all that*
• Prevention versus early detection	• *FG7: You can't prevent it but you can find out...*
	• *FG15: But it doesn't prevent the cancer does it? It just identifies it.*
	• *FG8: Yes, it can pick up in a Pap smear, cervical cancer if it's early, yes*
	• *FG19: It may not be there now but in 10 months time it could be.*
Trust	• *FG20: Saved my life, fair dinkum. As I had the final stage type of cancer, so if it wasn't acted on I might not be here today.*
	• *FG8: You have to trust it, because what is the alternative – is there any other test?*
• **Accuracy**	• *FG21: It's not always fool-proof.*
	• *FG10: About 10 or 11 years ago if I remember right, there was quite a scandal about one of the pathology firms or something and their results were all incorrect, do you remember that?*
• **'That extra test'**	• *FG2: There's an extra test that um, the patient has to pay for. If they want to go ahead and I always say yes ... I'm not sure exactly what it shows*
	• *FG13: To me it doesn't make sense – cause if that's a bigger, better test to do, why aren't they doing it as stock standard – I don't understand that.*
Compliance	• *FG10: I think our generation were sort of, the ones that when they were told to do something, we went and done it.*
	• *FG5: It's to do with one of those unspoken places – you get on and do – if you're told to go and have a Pap smear very two years you just rock along.*

The themes relating to the benefits of screening were consistent across all groups with the exception of liquid-based cytology that was raised in only half of the groups. There was much debate throughout this discussion as women seemed to have more familiarity with the subject given their previous experience with Pap smears.

7.6 PERCEIVED BARRIERS TO CERVICAL SCREENING

The question, *'What do you think prevents some women from having Pap smears or putting them off?'* prompted much discussion and women often laughed and joked about some barriers and shared anecdotal tales about their experiences. It was not uncommon for the whole group to break into laughter at some women's comments or stories, although at times there were also moments of anger or disbelief about others' experiences.

The most commonly identified perceived barriers to screening related to practical barriers, cultural barriers, fear and denial, dislike and discomfort - both physical and psychological, as outlined in Table 7.8. In the context of this discussion women also talked of how the Pap smear was often one part of a comprehensive women's health check, their prior negative experiences and how this procedure was largely different for them compared to their experience when having children.

Women also spoke about enablers that helped them to overcome some of these barriers including what they did, what the provider could do and system related enablers, such as reminder systems and services.

Women talked about competing pressures on their time, such as family and work commitments, difficulties accessing bulk billing for the consultation, financial pressures, being charged for pathology and having to pay for that 'extra test' which were themed 'practical barriers'. Access issues related to service continuity especially in country areas where doctors providing the service changed frequently or their regular provider retired. Having access to a female provider was important for some but not all women (Table 7.8).

Cultural barriers

Women referred to cultural barriers that they perceived may impact on some women. As the majority of women in the focus groups were born in Australia, these barriers were raised by women reflecting on the barriers women from other cultures may face (Table 7.8).

Table 7.8. Perceived Barriers to Cervical Screening from Focus Groups Conducted in Queensland, 2009.

PERCEIVED BARRIERS TO CERVICAL SCREENING	
Themes	***Exemplars***
Practical barriers	• *FG2: You don't get any bulk billing done up here.*
	• *FG19: And we've gotta wait three months for Dr x and pay $150 bucks for a double appointment plus your extra pathology on top of that –so if you can't afford it.*
	• *FG19:You get up the guts and you ring the bloomin' doctor and they can't fit you in for three weeks.*
	• *FG7: If you can get into a female GP, a lot of them aren't taking any new cases!*
	• *FG2: Probably because I was too busy working, and I was rearing children and I just didn't seem to find the time.*
Cultural barriers	• *FG6: The idea of modesty in a lot of cultures would be really hard to overcome – that barrier of exposure – like women who can only expose their face – how would they feel exposing their vagina?*
Fear/denial	• *FG12: Not wanting to know either way.*
	• *FG20: Fear, yeah, fear of what you might find out.*
	• *FG3: Or they are in denial, they don't really want to know, bury my head!*
	• *FG15: A lot of the young ones too it's again, 'I'm too young, it's not going to happen to me it's going to happen to somebody else'.*
Dislike	• *FG19: It's horrible.*
	• *FG8: It's degrading.*
	• *FG19: It's a) embarrassing, b) very invasive – you don't like it.*
	• *FG22: But it's just that it is something very personal and private – thank you!*
Physical Discomfort	
• Pain	• *FG2: Yes, one woman hurt me so much I never went back for five or six years!*
	• *FG22: And the scraping...*
	• *FG5: With me I had a male doctor and he hurt! He really didn't care that he hurt and when I said 'that hurts' he goes 'oh that's just normal' – I changed doctors after that and I've had no pain since and I just thought no, he's just too rough.*
• Cold instruments	• *FG14: That bloody cold silver thing! (laughs)*
	• *FG18: And poking those horrible cold instruments there –*
	• *FG13: I don't feel particularly embarrassed but it's just uncomfortable. Yeah, the cold speculum and that sort of screwing thing.*
Psychological Discomfort	
• Vulnerability	• *FG12: Uncomfortable - that is the main thing because I don't think it has a whole lot to do with the pain because there is no pain, it's uncomfortable but it is more uncomfortable if you are in a very vulnerable position I guess.*
	• *FG18: Well you are pretty vulnerable aren't you?*
• Invasiveness	• *FG18: The one factor that I find is I don't like is the invasiveness - even though I'm aware of it.*
	• *FG11: Very intruding indeed – invasive - I feel.*
• Embarrassment	• *FG7: Ah, no it's more the embarrassment I think, you've got time to lay there and think about what's happening.*
	• *FG21: Yeah, sticking our legs up in the air! (laughs)*
	• *FG21: The thing is, it's embarrassing to us, but the doctor doesn't like having to do it either – like he doesn't want to have people's legs stuck up in the air*

	– it's part of the job, so, it's embarrassing on both sides.
	• *FG2: Although my doctor said 'it's just like looking at the engine of a car love so don't worry'*
	• *FG9: Well that's actually true because we get really sweaty and that and you just think, well I'm not going there, it's too hot, not only is it uncomfortable for me but it's not really nice for the lady so.*
	• *FG7: But sometimes they used to have a nurse in the doctor's surgery if they had a male doctor. I think that was more embarrassing – a young girl!*
• modesty/ privacy	• *FG10: I did go to another GP and I felt so embarrassed at how he treated me. He stripped me off, I had this little skimpy sheet and the way I was treated I would have never gone back.*
	• *FG12: And letting somebody do that, you know it's a private thing.*
	• *FG23: Some people think I don't want a doctor looking down there! (inaudible and laughter)*
	• *FG18: Or they are going to see your rolls of fat. Or they are going to see something that you don't want people looking at.*
	• *FG20: It might be part of the job but still it's personal - I don't think you do ever get over that sort of thing and it seems to get worse as you get older.*
	• *FG16: You put your body somewhere and open your legs and say have a look at the most intimate part of my body – there you go!*
• familiarity	• *FG6: I feel really uncomfortable going to a doctor because I don't have a GP or anything like that – when I go to the doctor I see a different person every time.*
	• *FG21: That's it – it doesn't matter if it's a man or a woman I just don't feel comfortable with some strange person fiddling around.*
	• *FG5: I think it's embarrassing if you've got a family doctor, and you know that doctor's seeing you.*
	• *FG22: Goodness me, my GP is a female but I would never go to her for a Pap smear but I went to her birthday party the other week so that' s why – no way I would do that.*
• intimacy	• *FG13: It's a very intimate sort of thing – 'cause you know most people at work haven't seen your vagina!*
	• *FG10: My father did not like my Mother going…anything done down there. That's the 'down there', it's a clear area - it's his private territory.*
	• *FG22: Well it is very personal isn't it, for a woman, and I only do that with my husband, you know I don't look at the doctor as my husband.*
	• *FG5: Well I've only ever had one partner and he's the only other person who's ever touched … and that's why, you know.*
	• *FG6: I actually think a lot of women sort of hold back because it's the actual thought – well it's not my husband looking down on there – it's someone strange so you actually going to see and you're sort of thinking well it's not going to be private anymore.*
Well women's check	• *FG13: Participant 1: That feeling; Participant 2: And you think it's over and it's not!*
	• *FG5: Do you know what I often laugh about this- they say I'll just pop out of the room while you get undressed and then... you know it's like a picnic...He's got it all laid out and then he's got a little blanket that you cover yourself, you know, and then whatever end he's doing or both... you go through the whole rigmarole then, 'cause my doctor does the whole, you know, full head to toe*
Negative experiences	• *FG5: Actually I had a male doctor - when he did the Pap smear , made a comment and I thought that was really inappropriate.*
	• *FG14: Everyone knows Dr x, he says 'get your arse up here, sticks his coldest, hardest bloody... and says relax! Relax! What's wrong with ya?'*
	• *FG15: I had one of my daughters and she didn't want to have a Pap smear and had never had a Pap smear as she had been sexually abused and had this absolute fear of you know anything sexual basically and I'm sure there are other people out there –*
Akin to childbirth	• *FG7: I wouldn't think that after you have a baby anything could be embarrassing.*
	• *FG18: Yes but when you are my age, I mean that was 30 years ago, sort of thing, so that's sort of long gone –*
	• *FG5: When you get in that labour ward you don't give a damn- you don't care – when I was having a breech they needed the students to come and have a look and you don't care – do what you like – just get the thing out ! (laughs)*

Fear and Denial

Fear and denial were also barriers for some women. Fear did not just relate to having a Pap smear but was also associated with fear of being diagnosed with cancer and fear about having to have treatment (Table 7.8).

Dislike - It's yuk but we're still fronting up

Women consistently talked about this test very negatively as a health procedure that they endured because of the perceived benefits. The terms they used to describe the Pap smear included 'degrading', 'horrible', 'invasive', 'uncomfortable' and 'embarrassing'.

In-depth discussions occurred about discomfort and embarrassment which provided good insight into what these factors pertained to. These factors were discussed by women of all ages. The term 'uncomfortable' was used by women to describe both physical and psychological discomfort.

Women referred to physical discomfort and spoke of the provider as being 'rough', as hurting them and described pain associated with the Pap smear. It was not uncommon in these discussions for women to also describe how the provider often dismissed their discomfort telling them it was normal to feel pain. Women also spoke of the discomfort they experienced when a cold speculum was used and for some women; the position itself caused them discomfort.

Embarrassment

Psychological discomfort was a more complex theme which included sub-themes of vulnerability, invasiveness and embarrassment (Table 7.8). Embarrassment was an area explored in detail, as this is a frequently cited barrier in many studies and this provided insight into what women perceived as embarrassing within the context of having a Pap smear.

Sticking our legs up in the air!

Women often referred to the position as embarrassing and this was linked for some women to vulnerability. Women also referred to hygiene and how they were less inclined to have a Pap smear when the weather was hot. They often spoke of having their 'legs in the air' and closely linked to this was feeling exposed and the theme – modesty/privacy was used to describe this. Privacy and modesty issues included concerns about others being present, such as a chaperone and having others see parts of their body that they would not normally expose in public. Women also thought it must be an unpleasant examination for the provider and that it 'was embarrassing on both sides'.

Some strange person fiddling around!

Familiarity with the provider was important for some women but for others this was a barrier. If women were too familiar with their local general practitioner (GP), for example, they socialised with them, they did not want to have a Pap smear with them. However they also did not feel comfortable seeing a stranger.

It's a very intimate sort of thing

One concept that women described was intimacy and it was raised by women of all ages. Intimacy was described in terms of having someone else see or touch what they considered a special part of themselves with someone who was not their partner. On a couple of occasions this was raised as a control issue by some women, where they talked about how some men may prevent their partners going for the test.

Well women's check - It's like a picnic

Some women also described how the Pap smear procedure was often conducted as part of an overall health check and in conjunction with a breast and pelvic examination. These were referred to as a 'well women's check' (Table 7.8).

Negative Experiences

There were also recounts of negative experiences and inappropriate behaviours that women described as barriers, which included derogatory comments and the physical examination itself. Barriers associated with previous sexual assault were also raised by women and were included in this theme.

Akin to childbirth

The other thing discussed was whether the embarrassment experienced during a Pap smear was the same or different to that experienced during antenatal checks and this was a topic of much debate and discussion. For most women they felt more embarrassed having Pap smears than antenatal examinations as their focus at the time (the perceived benefit) was having a healthy baby.

7.6.1 Enabling Strategies to Assist Women Overcome Barriers to Cervical Screening

During the focus groups, strategies were also discussed to reduce embarrassment and enabling factors that made having a Pap smear easier (Table 7.9).

Provider - It's in the skill of their hands.

When women spoke about having Pap smears, provider related issues were described. Women referred to the provider's technique and the importance of having the procedure explained to them and their privacy respected, for example, locking the door, *"I've had some doctors not lock the door and the receptionist come in!"* There was a gender preference with many women preferring a female provider; however women who had either had a negative experience with a female provider or conversely, a positive experience with their male provider, did not prefer female providers.

Disengagement - Down there

Some women overcame their embarrassment by trying to disassociate themselves with what was happening 'down there' and wanted the procedure to be over and done with as quickly as possible. They often spoke of switching off as if their head and body were separated during the procedure.

System issues

Women also discussed alternative options which were themed 'system issues', as access to a nurse Pap smear provider and the one-stop shop concept where women could have a breastscreen and Pap smear at the one visit. These options were considered enablers that may assist some women to access cervical screening, particularly if they were free or offered at low cost. Women also liked to receive reminders from the PSR or GP rather than be faced with a Pap smear when they went to the doctor for something else (opportunistic screening) as this did not give them time to prepare for the procedure (Table 7.9).

Education - a lot of young people don't know

Education and awareness raising in schools about reproductive health and screening were other strategies raised by women that they thought would assist young women to understand the benefits of screening and what to expect.

New technologies - Find some other way of doing it

Women questioned why there had been little technological advancements in screening for cervical cancer such as a blood test. Within this context, women were asked about self collection and asked about a hypothetical test as follows: *"If there was a test you could do at home, say a tampon or swab you could insert yourself and send off in the mail, do you think women who don't go for Pap smears now might do it"?*

Table 7.9. Perceived Enablers for Cervical Screening from Focus Groups Conducted in Queensland, 2009.

PERCEIVED ENABLERS FOR CERVICAL SCREENING	
Themes	***Exemplars***
Provider	
• **Technique**	• *FG7: I don't think gender, in that it comes up – it's in the skill of their hands.*
	• *FG20: I know years ago I had one and I had a doctor there and he was always so nice he'd say 'now come on I've done this before' and you know, say just enough to make you relax and your body would relax too.*
	• *FG9: Yeah if they go through what they are doing instead of shoving things inside and out.*
• **Gender issues**	• *FG13: I don't care – it doesn't bother me – I don't care.*
	• *FG13: And if you only have a male doctor – I go to my female GP who's excellent – I know she gets bored to death ...But I think women on the whole, feel a lot more comfortable with a female GP.*
	• *FG10: I had a female and she was rough.*
	• *FG18: Well I think the guys explain it more because they know the sensitive nature. Whereas the girls think "oh yeah, we all know what it's all about"*
Disengagement	• *FG5: I just umm, I almost switch off – like as if I'm up here and what's down there is separate...*
	• *FG5: Disengage the head and think this is something you've got to do – get it over and done with as quickly as possible, get the instrument warm.*
System issues	• *FG10: Well why can't they have a Pap smearing clinics with the breast screening clinics?*
	• *FG15: Yes I think the cervical screening nurses do a good job, (inaudible), you know the amount of kilometres they travel is phenomenal.*
	• *FG1: Respondent 1: I know with me they don't send you a letter or anything to warn you, you turn up and the nurse says "by the way you're due" and you've got no time to think about it or mentally prepare or anything like that - Respondent 2: Or wear your good undies!*
	• *FG13: The Pap Smear Register is a real reassurance – you know people are chased up rather than trying to remember which year it was.*
Education	• *FG8: I think it might also be a lack of education, particularly amongst young women as to what it involves, what it's for, and even what age to start at because I still don't know what age you're supposed to start having a Pap smear, but I don't know what it involves, I don't know a lot about cervical cancer either to understand the push to have that testing regularly – and I think for a lot of young people that don't know about it*
New technologies	• *FG18: I say let's have research and find some other way of doing it, why do we have to have it like that, it's time - because it's been going on for years like that, we need something new and different that will do the exact same thing.*
Self collection	
• **Acceptability**	• *FG21: From my point of view I wouldn't have gone so long without it if I had something like that.*
	• *FG7: I think the majority would say oh forget about it.*
• **Practical issues**	• *FG2: Contamination.*
	• *FG13: Not do it properly and then sticking it in the mail – you get somebody else's mail and somebody might open it and good God!*
• **Prefer clinician**	• *FG13: I think I feel be more comfortable if I knew a professional was doing it, I'm not a professional at that.*
	• *FG19: I would have a bit of a problem with that actually - If you've had procedures done during your life and then you go for this type of test – it's probably one of those things that when you go to the doctor, he or she always goes through different other you know, examinations*
• **Options**	• *FG9: I reckon the best thing would be it to get different options to people so they can get the doctor to do it or decide to do it themselves and then maybe you'd get more people to do them.*
	• *FG21: I think it's probably a good idea , for people who aren't going to doctors in the first place –there's no negatives I suppose.*

Self collection

I think that would be wonderful!

It was surprising the number of women who supported this concept and how enthusiastic they were when it was first put to them. However there were also strong opinions against this option.

Practical issues were identified, such as whether they would contaminate the specimen or hurt themselves, and issues relating to the mailing and receiving of results. Women were also concerned that they may not do the test properly as "*I'm not a professional at that*", and whether the test would be as effective as one collected by a health professional. Despite differing views about self collection, there was the view that underscreened women may participate if they had access to this test, although not everyone thought this. Women also felt it was important to give women a choice so they could still attend a practitioner for screening if this was their preference (Table 7.9).

Women participated actively in discussions about barriers and enablers and some women disclosed openly they did not participate in screening. Women were highly engaged and motivated at this stage of the focus groups. Access issues and cost barriers were most often raised in areas of lower SES and in more remote communities.

7.7 PERCEIVED SUSCEPTIBILITY TO HPV

To ascertain women's perceptions about HPV, they were asked to describe what they knew about HPV through an open-ended question *"What do you know about human papillomavirus or HPV?"* The main themes identified under this topic were uncertainty, the natural history of HPV infection, how it was transmitted and whether it was preventable (Table 7.10).

Uncertainty was as a common theme when HPV knowledge was explored. There were three sub-themes of uncertainty. There were women who had not heard of HPV ('*don't know'*), many others who knew nothing more than the name and those who primarily had queries about HPV and requested clarification.

Of those who knew something about HPV, there was recognition that it was common and that HPV was an asymptomatic infection and frequently passed on without the infected person aware they were transmitting it.

Table 7.10. Perceived Susceptibility to HPV from Focus Groups Conducted in Queensland, 2009.

PERCEIVED THREAT OF AND SUSCEPTIBILITY TO HPV AND HPV KNOWLEDGE	
Themes	***Exemplars***
Uncertainty	
• **Don't know**	• *FG12: I dunno, I haven't heard anything about it!* • *FG11: I've never heard about it*
• **In name only**	• *FG7: I've heard about it but I don't know anything about it – I've only heard the name and that's it.* • *FG21: And when you don't know what it stands for, it doesn't mean much - I thought I must find out*
• **Queries**	• *FG11: Isn't papilloma a wart? – Ok that's what I know (lots of laughter) ... Only 'cause my little dog just had it and the vet called it papilloma!* • *FG14: I don't understand the link between the whole cervical cancer and the HPV thing – sorry!*
Natural History	
• **Prevalence**	• *FG18: I think it would be very, very common, I think a lot of people would have it.* • *FG15: It's an epidemic.*
• **Symptoms**	• *FG4: Males carry it and give it to females and don't even know they've got it.* • *FG18: Like a lot of the population would have it and a lot of them wouldn't know they had it.*
• **Impact**	
• link with cancer	• *FG12: Well it goes through stages; the virus goes through stages until it turns to cancer, I assume.* • *FG6: I'm not sure – my understanding of HPV is that you can suffer HPV and it can never convert over to a cancer, but on other occasions it will*
• misconceptions	• *FG22: That's the virus that, women are concerned about for when you have German measles when you are pregnant ...* • *FG18: And it's just lurking in there waiting until you are 35 are trying to have a baby and they say 'sorry you've had HPV since you were 15 and sorry'*
• **Warts or not**	• *FG18: I would say no - I know it's a wart virus but I don't think you have to have the warts – I reckon you could have HPV without the warts.* • *FG13: It's a different virus to the papillomavirus - the HPV.*
• **Treatment**	• *FG15: Oh no, you can treat the warts but you can't treat the HPV.* • *FG9: That's what I was going to ask in relation to treatment, what about the vaccine?* • *FG12: No, I don't know actually but maybe not – not always because it can go away – stop.*
Transmission	
• **Related to sex**	• *FG18: Well I thought after you were sexually active you could get it, not necessarily via sex but ... the virus could develop in your body by having sex.* • *FG19: If you haven't had sex you're not at risk as much and I think that's why they are giving the vaccine to young girls.* • *FG10: It's a virus. It is more likely if you've had multiple partners or your partner has had multiple partners.* • *FG8: The guys don't get problems but they give it to the girls.*
• **Other**	• *FG11: So if you are in the shopping centre and you shake someone's hand you're not going to get the virus?*
Prevention	
• **Safer sex**	• *FG13: I always just assumed that it was from the virus so if you have protected sex you are reducing your risk of ...*
• **Vaccination**	• *FG22: Isn't that what the girls are getting their injections for? So that is what it is stopping is it?*

There were often more questions than answers raised particularly about the impact of HPV and its association with cervical cancer, although it was not assumed that everyone infected with HPV would develop cervical cancer. There were also misconceptions about the impact of HPV on women's reproductive health such as infertility.

There was limited understanding about different types/strains of HPV and a few women questioned whether it was the same virus that caused genital warts (Table 7.10). There was also uncertainty and confusion about whether it was treatable, although some women were aware the body could clear the virus.

When talking about how HPV was transmitted, women often thought it was related to sex and most often a sexually transmitted infection, although there was uncertainty about whether the virus developed once a woman became sexually active or if males were the source of infection. Other modes of transmission were queried and classified as 'other' such as vertical transmission (from mother to baby during pregnancy or birth). Women queried if HPV could be prevented through the vaccine or if the vaccine was a treatment for HPV infection and safer sexual practices were also thought to help prevent HPV infection.

The age of participants was not necessarily indicative of women's knowledge about HPV as reflected in one observer's notes – '*Older women appeared more informed'* and uncertainty was widespread. Uncertainty was commonly expressed about this topic in almost half of the focus groups where most women did not know of HPV or had not heard anything other than its name.

7.8 PERCEIVED BENEFITS OF HPV VACCINATION

When discussing the perceived benefits of taking action through vaccinating against HPV, the main themes were awareness of the vaccine, acceptability, practicalities and concerns (Table 7.11). Cues to action were also discussed within the context of the information women would require to assist them to make an informed choice about consenting for the vaccine.

Awareness

Women were more aware of the vaccine than HPV, although there was still a lot of uncertainty expressed by some women and a number of older women had promoted the vaccine to their daughters and granddaughters (Table 7.11). Awareness of the vaccine was evident in all focus groups. Experience with the vaccine was also described as some young

women attending the focus groups had been vaccinated; others had consented for their daughters to have it whilst others spoke about their adult daughters having had it.

Acceptability

There was general acceptance of the vaccine, although vaccinating girls against HPV did raise some concerns about how this may promote sexual activity; however this was rare (Table 7.11). When consent was discussed, concern was raised by some women that parents were making decisions on behalf of their daughters and the importance of including girls in the decision-making process about vaccination was commonly raised.

Practicalities

Women knew girls/young women were eligible to receive the vaccine for free but gave varying ages and discussed whether or not it should be given before sexual activity as some heard it was only offered to girls before they became sexually active whilst others spoke of how young women in their 20s were able to have the vaccine for free. Women were uncertain about the number of injections in the course of the vaccine and even vaccinated women and those who had consented for their daughters, seemed unsure of this. The role of the vaccine in preventing genital warts was not raised in the context of the benefits of HPV vaccination in any focus group.

Concerns

Older women often wanted to know why they were not eligible for the free vaccination program and at times raised concerns about equity. This was sometimes linked with confusion about the effect of the vaccine as some women thought it had a therapeutic effect and so saw the vaccine as having benefits that were therefore not available to them unless they paid to have it (Table 7.11). The most commonly cited concern about the vaccine related to side effects. Women wanted to know about short term effects but also raised concerns about long term side effects that they believed may not have yet been identified given the vaccine is relatively new.

Cues to action

Women often spoke of Professor Ian Frazer and occasionally his colleague, Dr Zhou (who was not named specifically) when the vaccine was first mentioned and his role as a champion in raising awareness of the vaccine was evident even in remote areas. Women were also sceptical of anti-vaccine messages including negative media coverage.

Table 7.11. Perceived Benefits of HPV Vaccination from Focus Groups Conducted in Queensland, 2009.

PERCEIVED BENEFITS OF HPV VACCINATION	
Themes	***Exemplars***
Awareness	
• **Uncertainty**	• *FG21: Is that possible, is there one?*
	• *FG21: I've heard about it but that's all.*
• **Experience**	• *FG18: Yes, well mine fainted for the first one and she made me come for the second and third.*
Acceptability	• *FG14: I'm Grandma to 8 girls and I'm saying – 'get in there and get it, get in there and get it, get in there and get it!'*
	• *FG18: And if I thought it was something that would help prevent cervical cancer I would be in there like a shot.*
	• *FG5: Some people might feel – oh you're encouraging my child to have sex.*
• **Decision-making**	• *FG11: I think it's a big ask for a child of that age to, you know, for their parents to say you've got to have this, you know, because it could affect their life.*
	• *FG20: We are not even sure whether to advise the girls to get it or not, we've left the decision up to them because it's their body and their future*
Practicalities	
• **Eligibility**	• *FG2: They want young people to have it before they're sexually active.*
	• *FG13: They are not really recommending the vaccine for women in their forties say who have been married for a long time...*
• **How many?**	• *FG12: Yeah- They had them at school – the first one was at school and the second one was at work so then they sent me to some clinic down here.*
	• *FG1: You just have one needle.*
• **Treat or prevent**	• *FG20: I want to know if they can give a vaccine like that why can't they give us a vaccine to stop ... problems?*
	• *FG15: Yeah so if you've already got it, bad luck, if you have the vaccine you've got a ring of confidence.*
Concerns	
• **Inequity**	• *FG22: Yes but what does happen to the older women, is there something for us or, are we open to have that or is it only young women ...?*
• **Side effects**	• *FG5: Well I 'm not concerned about all vaccines – I gave all my kids their vaccines – it's just that one. It's the unknown I think.*
	• *FG11: You'd worry about the side effects I guess...if there's been enough research or time to know if there's side effects.*
	• *FG19: There was some reaction – the one girl who died...*
Cues to action	
• **Champion**	• *FG13: The cancer vaccine was very much helped by the profile of Ian Frazer - for me.*
	• *FG1: Like when he became Australian of the Year and something like that*
• anti-vaccine	• *FG1: There was a smear campaign going on about the immunisation.*
	• *FG8: There's been some controversy around the side-effects with it. The media jumped onto that one.*
• **Trusted source**	• *FG10: I want to see a lot more research with the truth about it ... perhaps it's too late to say, you know, so many years on 'oh gee, sorry girls you were the first batch and we forgot to tell you that there is a problem'*
	• *FG14: I also don't think the medical profession would bring out something like the vaccine if it had not been tested over a long period of time*
• **Benefits**	• *FG10: And I'd like to know is how many people are affected from the vaccine? Is it 1 in 100, is it 1 in 1000 or is it 1 in 1000000. I mean what is it?*
	• *FG11: ... they say you're supposed to get it – but where's the proof that it has worked*
• **Pay more attention**	• *FG13: It's comes with the information and consent and so on – I mean I would presume the child's been told about it at school. But I'm thinking – gosh maybe I should be telling them about it.*

The role of providers as a trusted source of advice was raised in focus groups and influenced some women's decisions about having the vaccine. Some women questioned why they put so much faith in the medical profession whilst others trusted the vaccine because it would not be supported by doctors unless it was safe.

When discussing the information they wanted to know about the vaccine, the effectiveness and proof that the vaccine worked was considered important and women wanted information upon which to balance the benefits versus the harms of the vaccine, including the risks if a girl was not vaccinated.

Pay more attention

There was recognition amongst women about how little they knew about vaccinations and a realisation that they had become somewhat complacent about them as although information was sent home from school, they did not always read it and just signed the consent forms. Specific to the HPV vaccine though, was that for many women it was not seen to be relevant to them as they did not have daughters or were not eligible for it and therefore had not sought or accessed further information – *"Isn't it terrible? I didn't pay much attention, because I don't have daughters"*.

Discussion about the vaccine was not as lengthy or detailed as the previous discussion about Pap smears and highlighted women's uncertainty about specific details related to the vaccine. Knowledge about the vaccine differed across groups with some older groups knowing very little about the vaccine but this was not consistent. Overall women were highly accepting of the vaccine, had limited knowledge about the eligibility criteria and were mostly concerned about side effects, especially in light of this being a relatively new vaccine.

7.9 CUES TO ACTION – INFORMATION SOURCES AND ACTIVITIES

The final topic discussed in the focus groups related to cues to action and sources of knowledge about cervical cancer prevention. The first question women were asked in this section was '*Where do you get your health information from*?' Women described the sources they trusted, which included their GP and the pharmacy.

Women also talked about 'word-of-mouth' and those who were members of women's organisations (QCWA and Zonta International) or women's health groups spoke of how they often had guest speakers talking about health topics. They had varying views of the Internet but considered health websites were a reliable source of health information.

Few women accessed magazines for health information as many women thought they were expensive and did not consider them a reliable source of advice. Women recalled television advertising and posters they had seen about cervical screening and referred to the key message in the recent QCSP campaign, although they had varying views about it.

- *The ad on TV I'm sure it says you can get this HPV virus even if you've only had sex just once it said.*
- *With that revolting picture.*
- *I don't like seeing that on television. It's just too personal and for the whole world to see. You don't want every man and his dog virtually seeing that sort of thing.*
- *With TV if it comes through as an ad, I'm sorry, the ad can be there in front of me and I wouldn't have a clue what it's about – I turn off – but as soon as the program comes on – yeah!*
- *But those Pap smear ads when you sit down at night and you're having your cup of coffee – it's made me twice go and have my Pap smear.*

Women were then asked how they thought the Queensland Cervical Screening Program (QCSP) should disseminate new information for women about cervical screening – *'There is a possibility that there will be major changes to the Pap smear program over the next few years so what do you think would be a good way for us to get new information out to women'?* Women talked about the sources of information they had previously discussed as sources of reliable health advice, such as mass media, networks, schools, health providers and the Internet but novel approaches, and sending letters to women on the PSR were also discussed (Table 7.12). There was also a notable change in women's description of strategies whereby they used more active language about how the QCSP could engage with women and successfully communicate policy changes.

Diversity - There's not one way

Women frequently referred to the need for multiple approaches due to the diversity of women by age, culture, location and other factors including literacy as women showed concern about specific groups or areas when suggesting strategies and were not just focused on their own needs.

Mass media - Go to the masses

Women felt mass media was relevant and it was deemed important to ensure optimal reach. Women recalled television advertising and posters they had seen about cervical screening, although they felt there was little exposure and discussion about cervical cancer in the public domain especially compared to other cancers, particularly breast cancer. Television programs in particular were considered effective and women thought they were a good way to promote health messages, especially when the topic was integrated into the storyline or a real life story was portrayed. Women did not think advertisements in women's

magazines would be that effective; however magazines that focused on health issues or specific groups, such as young women or girls, may have a role to play. Convenience advertising, such as notices on the back of toilet doors were considered an effective strategy that they recommended as they were a captive audience and often read these messages when using public facilities. In addition, having a high profile media personality was thought to be effective, although they did acknowledge it might be difficult to find someone who would be prepared to publicly announce they had cervical cancer.

Networks

Women also felt they had a role to play in disseminating knowledge via word-of-mouth and how women's groups, such as the ones they were members of, were effective especially as older women often provided health advice to younger women (Table 7.12).

Novel approaches

There were a number of novel approaches raised including mail drops, advertising in women's change rooms and having specific events for prompting awareness of cervical cancer. Women did caution on over-exposure though and commented on occasion that women were tired of breast cancer messages, especially at special events such as Mother's Day, and also acknowledged the limitations of promoting cervical screening given the sensitivities involved.

Trusted sources

Women also felt health providers and services including pharmacies were important and were well placed to provide cues to action, especially as highlighted earlier, they considered them to be a common source of reliable health information. Putting information in school newsletters and education in schools was also raised as an important place to begin education and awareness raising in the community and not just amongst girls (Table 7.12).

Internet

Websites and the Internet were considered relevant for young women, particularly a focused health website and women also thought social media sites such as *Facebook* may be relevant for younger women.

Targeted strategies

When asked about sending a letter via the PSR, it was readily accepted. Women were concerned, though, that not all women would be reached this way, especially those who did not have Pap smears, as this was an important group to reach. It was also apparent women

were unsure if they were registered on the PSR and some felt it was not as effective as the BreastScreen Queensland Register who sent invitation letters, as the PSR only sent a letter if they were overdue.

If a letter was sent via the PSR, women felt they would be more likely to open it if it looked official with a logo and was personally addressed to them. They wanted the content to be simple, clear and concise and felt something to catch their eye, for example a header 'Important health information for women', would encourage them to read the contents.

Early communication

Women also felt it was important to begin communicating with them early if changes were to be made to the NCSP, rather than trying to convey a lot of information in a short time frame as they did not think this would be very effective.

Women were very engaged throughout this discussion and suggested many methods to communicate new messages and cautioned against relying on one or two ways to reach women given the diversity of ages, cultures, geographical locations and literacy levels of the target audience.

There were similar themes identified across all groups, although it was evident in a few groups that there were participants with marketing or health promotion expertise, which was reflected in their responses.

Table 7.12. Cues to Action – Recommendations to Disseminate New Information from Focus Groups Conducted in Queensland, 2009.

CUES TO ACTON – DISSEMINATION OF NEW KNOWLEDGE	
Themes	***Exemplars***
Diversity	
• **Multiple strategies**	• *FG1: No, because some people can't read, some people haven't got TV – you just need the media and have different formats and a cross-section of ages and cultures and having stuff in different languages.*
	• *FG19: Yes, I think there's not one way – hit it as many times as possible.*
Mass media	• *FG2: I believe the media is one way to push health messages.*
	• *FG7: I don't think there's ever enough advertising of things like that.*
	• *FG1: If it's something new then go to the masses, maybe radio, TV and –eventually you think, oh OK, there's something I do need to know about that.*
• **Television**	• *FG5: I think TV coverage for the illiterate parents; they can't read so they're not going to sign a form for an injection if they don't know what it's for.*
	• *FG10: Well I found I often watch A Current Affair or those types of programs and if something takes my interest on that I will look into it further, I will use the Internet to find out more.*
• **Radio**	• *FG11: They have radio talkback and they have different – they have a topic - we're going to talk about this topic today – get your views. But they also have a professional there and you can ask him questions, talk back and it's all thrown over. You have to be willing to talk about the virus – but then you have the ones that are private and they don't want to talk but...*
• **Print**	• *FG19: Major newspapers like the Australian or the Courier Mail.*
	• *FG7: I was just thinking, there's a couple of good magazines that have good health things in them.*
	• *FG22: Yeah, I don't buy women's health magazines*.
	• *FG1: I wouldn't get it from New Idea – I'd get it from my doctor*
• **Convenience**	• *FG12: I think the fact that we all have seen advertising is pretty good feedback – you know we've all seen the ad on the back of the toilet doors, so...*
• **Champion**	• *FG4: But I do think it needs to be open more in the broader community. The way Sarah Henderson came across with breast cancer.*
	• *FG1: You have to have a famous person who's actually a survivor of cervical cancer who's a well known identity*
Networks	• *FG10: I think word of mouth – go back to our branches and talk about this and it will then spread to the wider community and word of mouth is always far better for education than something on the TV.*
	• *FG4: We need more education in private groups like this, where you feel more comfortable to talk about it.*
	• *FG18: Women talk, women get together and talk.*
	• *FG1: I'm thinking of informing the older women... not for their benefit but informing the older woman's benefit but for the benefit of the younger women. If they are worded up they can help people who are younger –*
Novel	• *FG19: Do you put it in the power bill like they put your bloody ambulance letter– I mean everyone seems to get one of those.*
	• *FG1: Why don't you send something to people to catch the market you don't already have – (inaudible) – it might cost a bit to send it to all the houses - like just a postcard (inaudible) like one side of the thing says 'have you had a check" call this number – something little – short and sharp.*

	• *FG19:The Melbourne Cup luncheon here was breast cancer but I've never seen a Melbourne Cup lunch for cervical cancer...*
	• *FG1: Participant 1: What does everyone do? we shop – so even if you had like Katies, your underwear stores or things like that – have it in an appropriate place …: Same as a woman from a different culture – she might be afraid to talk to her mother or father or husband about it but she goes shopping – she's gotta buy clothes. So that pamphlet will be there for her in the change room* *Participant 3: But I really like the change room idea – what a great idea! Because you can close the curtain / door and no-one knows you're reading it*
	• *FG15: Well you're not going to stick it on the side of a bus.*
	• *FG5: In the libraries when I get my books I bring free leaflets of what's on. If there's a free DVD there I'll take it home and watch it that night and my husband will too.*
	• *FG5: Participant 1: Maybe you get Woolies and Aldi and Coles to put them in their bags as you go through the checkout– well you get a wider audience. Participant 2: I can just imagine this little old man coming home with his shopping!*
Trusted sources	
• **Clinics**	• *FG2: I think we're better to continue the education that this is thing to do, you know, go to the doctor and push the education side for young women.*
	• *FG22: Well doctors would know of course. Doctors themselves would have that information.*
	• *FG15: Indigenous Health Workers, our Indigenous Health Workers.*
• **Schools**	• *FG15: Yes it really sticks in your mind when it's at school.*
	• *FG5: If you were trying to go for the younger group you could go probably look at your local schools*
Internet	• *FG13: More information on a reliable website*
	• *FG5: No. I don't think so. My daughter isn't going to go to the website unless she knows there was something wrong with her then she would go. But most young ones aren't going to look up cervical cancer.*
	• *FG18: Yeah, Facebook has all those ads down the side and every time you log on you have a whole column of ads and they are targeted to the age group because as soon as you do something then suddenly you get ads relevant to that so it's very cleverly put together.*
	• *FG15: But for the X and Y generation it might need to be YouTube, Twitter...*
Targeted	• *FG18: But I think with a lot of the Pap Smear Register is... well are you aiming for the women who aren't getting them?*
	• *FG13: To me the key would be that the information is particularly important for your age bracket – maybe focused on your decade.*
	• *FG13: If it's addressed to you personally by name so I'm sure you know, women within your age group, blah, blah, blah.*
	• *FG10: Not necessarily the Queensland Health but from a symbol quite pertinent to Pap smears.*
	• *FG21: You usually come out with the government logo on it so you know it's from the department so you usually open it up to see what's in it before you throw it away.*
	• *FG12: Not to the householder – its junk mail – my husband would throw it.*
	• *FG16: Say if you said 'what every woman needs to know'.*
Early communication	• *FG14: So if you're changing the program because you're gonna have to do a lot of lead up work rather than just saying we're changing in a few ads and that 's it – this is going to have to be a big education program around whatever changes there are.*

7.10 SUMMARY OF FINDINGS

Women participating in the focus groups provided in-depth insight into their perceptions about their ability to have some control over their own health, their susceptibility to cervical cancer and HPV, the seriousness of it to their health and its impact on their lives, the benefits of participating in screening and vaccination, the barriers to participation in cervical screening and the cues that would enhance their ability to participate in screening and vaccination. The main themes identified from the focus groups are outlined in Figure 7.2.

Overall, women had very positive attitudes towards cervical screening and vaccination. Despite their negative attitudes towards the Pap smear procedure they felt it was important in protecting their health and therefore were accepting of it and compliant with screening even though they had limited knowledge about the purpose of the Pap smear as a secondary prevention strategy, when to start and stop screening and what an abnormal Pap smear meant. Trust, particularly of their health provider was an important factor that shaped their attitudes towards both cervical screening and vaccination.

Women's knowledge of the causes of cervical cancer and the associated risks of acquiring disease were limited. There was a great deal of uncertainty and misconceptions associated with this and women acknowledged they had not thought much about it and related this to limited personal experience with, or community awareness about cervical cancer, particularly when compared to breast cancer.

Women had heard of HPV, although often they had heard of the name but little else. They had also heard of the vaccine and again had limited knowledge about this, which they considered was due to their limited experience with vaccination given they were not eligible for it or did not have daughters.

Women's beliefs were strongly influenced by their experience, attitudes and knowledge about cervical cancer, screening and vaccination and they expressed concerns about the long term side effects of the vaccine, the harms versus benefits of Pap smears and the vaccine, and discussed factors, within and outside their control, that impacted on their health and their ability to participate in screening. Within their discussions, women also made many assumptions throughout the discussions, particularly about young women and their sexual behaviour and perception of risk for cervical cancer.

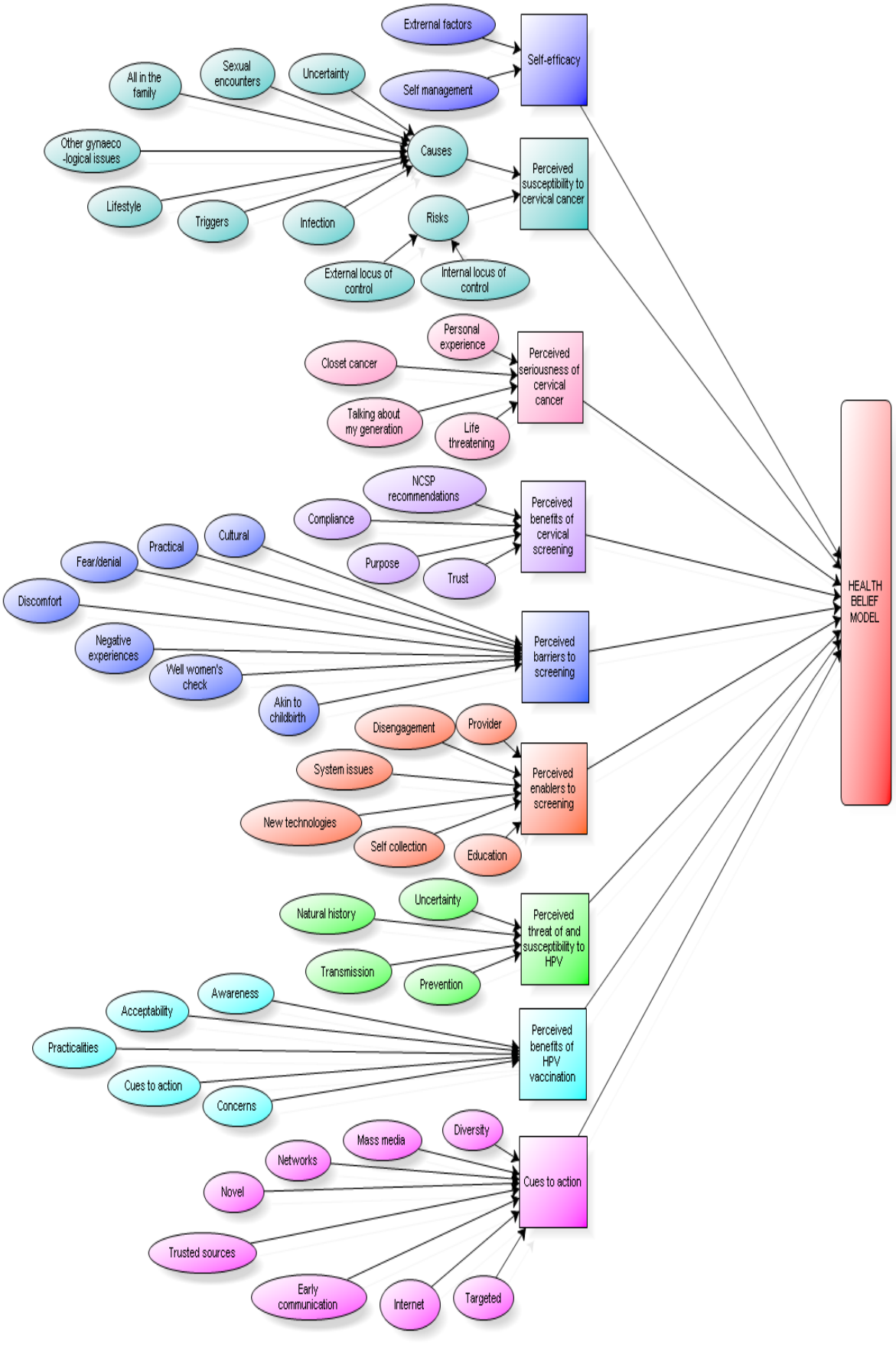

Figure 7.2 Summary of themes from focus group data

One of the most fruitful parts of the discussion was the issue of barriers and enablers associated with cervical screening. These related to individual barriers, such as discomfort, embarrassment, fear, denial, and revealed that the Pap smear is a test most women would prefer not to have. Within the context of this discussion, women were empathetic to those who did not participate and had many ideas about enabling factors to assist women to participate more easily, including the one-stop shop concept and the need for a less invasive procedure.

Participants also had many ideas on ways to communicate new information about changes to the NCSP. They considered it very important to use multiple methods of communication including personalised letters, mass media using a high profile personality and social media to ensure reach and accommodate the diversity of women in the target population.

The findings of both phases of this study are discussed in the next chapter with reference to relevant literature.

Chapter 8: Discussion

This chapter discusses the combined research findings from Phases 1 and 2 of this study in the context of the Health Belief Model (HBM) and how they relate to the findings of existing research. The characteristics of women who participated in this study are described in Section 8.1, women's perceived susceptibility to cervical cancer and human papillomavirus (HPV) is described in Section 8.2, and their perceptions about the seriousness of cervical cancer and HPV are described in Section 8.3. The benefits women perceive to result from cancer prevention strategies are discussed in Section 8.4, followed by the barriers they describe when considering screening and vaccination in Section 8.5. Cues to action including enablers for screening and information needs about new technologies, where women get their health information from and what they recommend for communicating and promoting information in their communities is described in Section 8.6 and the chapter concludes with a discussion about the applicability of the HBM to this study in Section 8.7.

This descriptive study provides unique insight into the beliefs underpinning Queensland women's knowledge about the causes of and associated risks for cervical cancer, their perceptions about cervical screening and HPV and their attitudes and concerns about the HPV vaccine. There was consistency between the results of each phase of the study with the findings of the computer-assisted telephone interview (CATI) survey, supported and expanded upon in the focus groups. The following sections highlight the meaning of these findings as they apply to the future of primary and secondary prevention of cervical cancer in Australia.

8.1 CHARACTERISTICS OF WOMEN IN THIS STUDY

Women who participated in this study ranged in age from 18–88 years and were middle aged and came from differing geographical locations across Queensland (Table 5.1; Table 7.1). Women participating in the focus groups were older and more likely to be from inner regional areas than CATI survey participants. Women were predominantly born in Australia and a representative number of women were Indigenous Australians. Most women were well educated and had completed post

school qualifications, the majority of which were at the certificate/diploma level. The majority of women were in married or defacto relationships and had children.

8.2 PERCEIVED SUSCEPTIBILITY TO CERVICAL CANCER

8.2.1 Causes and Risks

Perceived susceptibility to cervical cancer amongst women in this study was found to be based on limited knowledge and high levels of uncertainty of its causes and risk factors, which is a common finding in the literature. Marshall et al (2007) reported 79% of participants (both male and female) responded 'don't know' to an open-ended question about the cause of cervical cancer in a South Australian telephone survey. English women involved in clinical trials for HPV testing also knew little about cervical cancer and did not tend to talk about cause in the context of cervical cancer whilst 51% of British women in another study were also found to be uncertain about what caused cervical cancer (Waller et al., 2005; Marlow, Waller and Wardle, 2007).

In both phases of this study uncertainty about risk factors associated with cervical cancer was found, a common finding irrespective of where the study is conducted (Wong, 2011; Shand, Burney and Fletcher, 2010; Moreira et al., 2006; Waller, McCaffery and Wardle, 2004a; Mays et al., 2000; Pearlman et al., 1999).

Family history was incorrectly considered a risk factor for cervical cancer by almost 90% of the women in this study. Family history and its potential link to cervical cancer is not frequently documented in Australian studies (Agius et al., 2010a; Shand, Burney and Fletcher, 2010). It was reported as a risk factor by 74% of Thai immigrant women who participated in a study in Brisbane and has been frequently reported in a number of overseas studies, although in studies using unprompted recall, family history is uncommonly identified by women (Jirojwong and Manderson, 2001; Oscarsson, Wijma and Benzein, 2008; Cooper, Polonec and Gelb, 2011; Vanslyke et al., 2008; Marlow, Waller and Wardle, 2007; Waller et al., 2005; Waller, McCaffery and Wardle, 2004a; Mays et al., 2000; Baay et al., 2004). The implications of this is that if women do not have a family history of cervical cancer, which is highly likely in the Australian context, they may perceive themselves to be less susceptible to it, despite there being no links with family history or genetic factors in current cervical screening health promotion messages.

The relationship of smoking as a cofactor in the development of cervical cancer for HPV positive women was poorly understood by women in this study, consistent with previous findings (Agius et al., 2010b; Armstrong and Murphy, 2008). Similar to previous findings, women who reported they were smokers in the CATI survey were more likely to be underscreened and to have had a history of an abnormal Pap smear (Agius et al., 2010a; Smith et al., 2011).

Women in this study were uncertain about the contribution of other lifestyle factors, such as stress, being overweight and hygiene to the risk for cervical cancer. Immigrant Thai women also associated poor hygiene with cervical cancer despite the lack of evidence to support this (Jirojwong and Manderson, 2001). In unprompted studies, hygiene and dietary factors are also rarely cited as risk factors (Marshall et al., 2007; Waller, McCaffery and Wardle, 2004a).

Most women in the CATI survey did not consider high parity and oral contraceptive pill use to increase the risk of cervical cancer although these factors have been linked with cervical cancer in previous studies (Bosch and de SanjosÃ, 2003; Bosch and Muñoz, 2002). Most women identified not having regular Pap smears as a risk factor for developing cervical cancer in both the CATI survey and focus groups, a similar finding to a study of rural Victorian women (Hancock et al., 1996). This suggests that most women are aware not having regular Pap smears increases a woman's risk of cervical cancer; however almost a quarter of the women in this study did not think this. The underlying reasoning behind this finding is described in more detail later in Section 1.4.1 in relation to the perceived benefits of cervical screening.

In summary, this means that compared to previous work, uncertainty about the causes and risks for cervical cancer amongst women remains high, and there is a common misconception that family history increases risk. Future educational materials and strategies need to highlight HPV as the necessary cause of cervical cancer and the risk factors associated with the acquisition of HPV to increase women's knowledge of cervical cancer and assess their own personal risk.

8.2.2 HPV Awareness

There was high awareness of HPV with just over 60% of women in this study having heard of HPV previously, which was higher than found in Victoria in 2006,

but similar to that found in an Australian CATI survey of men and women, conducted in 2008 (Pitts et al., 2007; Pitts et al., 2010b). Higher awareness of HPV has been found in Australian studies when compared with overseas studies, which has been attributed to the introduction of the HPV vaccine in 2007, although awareness amongst younger women has been found to be limited in high school and university students, despite many having had the HPV vaccine (Pitts et al., 2010b; Shand, Burney and Fletcher, 2010; Wong, 2011; Huang et al., 2008; Marlow, Waller and Wardle, 2007; Agius et al., 2010a; Juraskova et al., 2011). Juraskova et al (2011), attributed this finding to the marketing of the vaccine as a cervical cancer vaccine rather than a vaccine against HPV.

There have been limited studies that have explored factors influencing HPV awareness that is, having heard of HPV, as most have investigated predictors of knowledge. Education was found to be an independent predictor of HPV awareness in this study, which was also found in a British study of women aged 16–97 years of age and a study of older women (50–80 years) in America (Marlow, Waller and Wardle, 2007; Huang et al., 2008). This difference observed in HPV awareness by education suggests that the communication strategy used for promoting the HPV vaccine in Australia, which primarily consisted of print media, the Internet and radio, may have been more effective amongst women with higher education levels and subsequent high health literacy (von Wagner et al., 2009; Leask et al., 2009).

Although not statistically significantly different, somewhat lower proportions of women over 60 years of age had heard of HPV than younger women (Table 5.8), which has also been observed in two overseas studies (Marlow, Waller and Wardle, 2007; Huang et al., 2008). Awareness amongst CATI survey participants was also impacted by women's prior experience of an abnormal Pap smear and their knowledge of cervical cancer/screening and reflects the findings of studies conducted with women attending dysplasia clinics or participating in vaccine trials (Giles and Garland, 2006; Waller et al., 2003). Pitts et al (2010b), found differential awareness depending on cervical screening status; however this could not be assessed in this study due to the low proportion of unscreened women.

Whilst there was high awareness of HPV in this study, the findings of both the CATI survey and focus groups indicate HPV awareness does not equate with good or correct knowledge, which is consistent with the findings of other studies (Shand,

Burney and Fletcher, 2010; Pitts et al., 2007; Waller et al., 2003). Whilst awareness appears to have increased somewhat over time from 12% in 2006 to 51% in 2007 and 63% in 2008, uncertainty about HPV persists in the community (Pitts et al., 2010b). In focus group discussions, it was not uncommon for women to say they had heard of HPV or articulate the name but no further knowledge was available about its role in cervical cancer or its functionality, which was consistent with the findings of other qualitative research conducted with Australian women (Cooper Robbins et al., 2010a; Rosenthal et al., 2007). Uncertainty about HPV in this study is consistent with the findings of other studies in which 'don't know' is a common response to knowledge items in HPV knowledge scales (Agius et al., 2010b; Shand, Burney and Fletcher, 2010; Pitts et al., 2010b). This suggests women had superficial awareness of 'the virus' but this awareness of HPV did not equate to knowledge to inform decision making about screening for HPV.

Uncertainty about the role of HPV as a causal or risk factor for cervical cancer has been identified in numerous studies conducted in Australia both prior to and following the introduction of the HPV vaccine (Agius et al., 2010a; Pitts et al., 2010b; Shand, Burney and Fletcher, 2010; Marshall et al., 2007; Pitts et al., 2007). HPV was identified as a risk factor for cervical cancer by almost 74% of women in Phase 1 of this study, which suggests awareness of the link with HPV and cervical cancer is increasing in the community. This was slightly higher than the 54% of women who associated it with cervical cancer in the 2007 Victorian CATI survey, but was consistent with the findings of another Australian study conducted during a similar time period, (2008), in which 72% of women associated HPV with cervical cancer (Pitts et al., 2010b; Pitts et al., 2007). Despite increasing awareness of HPV, uncertainty about its link with cervical cancer has been found to be higher in very young women, even if vaccinated against HPV, and older women (Pitts et al., 2010b; Agius et al., 2010a).

A large proportion of women surveyed (83%) indicated that certain types of HPV cause cancer of the cervix in the HPV Knowledge Tool, also consistent with other studies conducted after the introduction of the National Human Papillomavirus Vaccination Program (NHPVP) (Gerend, Lee and Shepherd, 2007; Juraskova et al., 2011; Pitts et al., 2010b). The proportion of women in this study who thought

certain types of HPV caused cervical cancer was almost four times that of young American women surveyed in 2003 (Table 8.1), (Kahn et al., 2003).

Table 8.1: Comparisons between HPV Knowledge in Current Study and Kahn et al, 2003

	Current study		(Kahn et al., 2003)
	Correct	Don't Know	Correct
	%	%	%
A person may be infected with HPV and not know it	94	5	51
Those with HPV may need Pap smears more often	85	10	49
HPV is spread through sexual intercourse	77	13	45
There is a vaccine to prevent some types of HPV	71	22	n/a [a]
Women can often clear HPV without treatment	12	18	n/a[a]
HPV can cause problems with pregnancy	9	27	16
HPV can be cured with antibiotics	49	34	41
HPV causes women to have abnormal periods	32	39	37
If you have HPV, smoking can increase your chance of cervical cancer	58	26	n/a [a]
Condoms do not always help protect you against HPV	61	16	34
Certain types of HPV cause cancer of the cervix	83	13	21
The Pap smear is a test for HPV	54	15	44

[a] n/a items not measured by Kahn et al(2003)

Whilst many women surveyed knew HPV was associated with cervical cancer, as in other studies, women had varying understanding of the aetiology of cervical cancer and their perceptions about their susceptibility to infection with the virus were therefore based on uncertainty and misconceptions (Cooper Robbins et al., 2010a; Waller et al., 2005; Vanslyke et al., 2008). There was considerable uncertainty about a number of HPV knowledge items, although women in this study were more likely to identify risk and protective factors than those participating in the study from which the HPV Knowledge Tool (Table 8.1) was derived (Kahn et al., 2003). However, women in the Kahn et al (2003), study were younger and varied in all socio-demographic characteristics to women in this study, and the study was conducted prior to the introduction of the vaccine.

A smaller proportion of young women, similar to that found by Kahn et al (2003), were aware of the asymptomatic nature of HPV in a recent study of psychology students in NSW; however this was a small, non-representative sample

(Juraskova et al., 2011). Increased knowledge of the sexual transmission of HPV and the limitations of condom use is evident in the present study when compared with studies conducted prior to the introduction of the vaccine (Pitts and Clarke, 2002; Waller et al., 2005; Baer, Allen and Braun, 2000; Giles and Garland, 2006). The relationship of HPV with sex and the notion that sexual activity is a trigger that activates the virus was also discussed in a previous study involving adolescent girls who had been vaccinated (Cooper Robbins et al., 2010a).

There was also uncertainty expressed about genital warts as a risk factor amongst women in this study which has been reported in other studies where the use of the term 'wart virus' was found to increase the stigma surrounding HPV (McCaffery and Irwig, 2005; Friedman and Shepeard, 2007). Uncertainty was also evident amongst high school students with 80% of students not knowing if HPV caused genital warts, although in a study of adult Victorian women, over 60% of women knew of this association (Agius et al., 2010a; Pitts et al., 2007). Of note is that only 45% of women surveyed in the 2008 Australian CATI survey knew HPV caused warts, despite this study occurring after the introduction of the HPV vaccine in Australia. This suggests the prevention of genital warts is not a widely recognised benefit of the vaccine and that there is limited community awareness that genital warts are associated with HPV (Pitts et al., 2010b).

The finding that women in the CATI survey with lower HPV knowledge were also more likely to have below average cervical cancer/screening knowledge and lower awareness of and negative attitudes towards the HPV vaccine is consistent with other studies (Shand, Burney and Fletcher, 2010; Pitts and Clarke, 2002; Mays et al., 2000; Kahn et al., 2003; Marshall et al., 2007).

Confusion about HPV and its relationship with cervical cancer and the vaccine was evident in this study and has also been reported in a recent Australian study of girls and parents post vaccination implementation. These authors suggested this could have been caused by the absence of information about HPV in public health messages about the 'cervical cancer vaccine' (Cooper Robbins et al., 2010a; Juraskova et al., 2011). Further discussion about the avoidance of explicit messages about the vaccine's role in preventing HPV, a sexually transmitted infection, has therefore been seen to have negatively impacted on community awareness about HPV and its link with cervical cancer and is a missed opportunity for raising

awareness within the context of promoting the vaccine (Cooper Robbins, Pang and Leask, 2011; Leask et al., 2009).

Placing the present study into context thus suggests that uncertainty and poor knowledge of the natural history of HPV infection persists in the community despite evidence of increased awareness of HPV. Education is required to inform the community and reduce uncertainty about HPV through, for example, patient information materials and mass media activities, and should be monitored in subsequent studies to determine the effectiveness of these strategies.

8.2.3 Sexual Behaviours as Risk Factors

Women, whether they knew about HPV or not, often linked cervical cancer with sexual activity, although there was uncertainty about whether it was the mechanical act of sex, sex as a trigger or the acquisition of a sexually transmitted infection. Trauma-based explanations, such as frequent sex or childbirth, and triggers including hormonal changes during menopause or pregnancy, have been identified by women as risk factors for cervical cancer in other studies (Armstrong and Murphy, 2008).

Limited knowledge that early sexual debut increased risk has also been found in a study of high school students who reported lower awareness of this as a risk factor and much higher levels of uncertainty than the women in this study (Agius et al., 2010a). Women in the focus groups assumed girls today were much more likely to engage in sexual activity at a younger age than they did, which is supported by research showing earlier sexual debut amongst younger cohorts of Australians (Boyle et al., 2003; Agius et al., 2010b).

There was discussion and debate about whether having multiple partners increased women's cervical cancer risk, which is consistent with the findings of a United Kingdom (UK) study (Armstrong and Murphy, 2008). Thai women in a Brisbane study reported similar levels of agreement with the women in this study about multiple partners as a risk factor for cervical cancer (77% and 72% agreement, respectively), as did Year 10 and 12 students (74%) in the high school study (Agius et al., 2010a; Jirojwong and Manderson, 2001). These findings suggest women associate sex-related behaviours with cervical cancer, however there is much uncertainty about who is at most risk, especially within the context of HPV.

Waller et al (2005), reported similar findings about the relationship between cervical cancer, HPV and sex in a qualitative study of women in the UK. There were three main groups of beliefs identified, those who believed cervical cancer to be unrelated to sex, others who thought it could possibly be related to sex and those who linked both cervical cancer and HPV to sexual activity (Waller et al., 2005). Those who knew of the link between cervical cancer and HPV as a sexually transmitted infection were more readily able to integrate new information about HPV into their existing causal framework than other women in the study (Waller et al., 2005). Armstrong and Murphy (2008), stressed the importance of health authorities being open about HPV as a sexually transmitted infection, as women otherwise weave their own meanings from health messages that are not explicit.

Failure to openly talk about sex-related risks for cervical cancer and normalise the risk of acquiring HPV was found in a New Zealand study to promote the notion that cervical cancer was linked to 'promiscuity'. This was found to lead to increased stigma but also led to some women not perceiving themselves to be at risk, particularly women in long-term monogamous relationships or those who have only had one or two partners (Braun and Gavey, 1999). Married women in an American study also did not perceive themselves to be at risk of HPV or consider information about it to be relevant on hearing it was a sexually transmitted infection (Friedman and Shepeard, 2007).

In a number of studies, when faced with a positive HPV DNA test, women have been reported to respond with shock, anxiety or fear, which has been attributed to poor knowledge about HPV and the stigma associated with the diagnosis of a sexually transmitted infection (Brown et al., 2007; McCaffery et al., 2006; Maissi et al., 2004; Kahn et al., 2007; Braun and Gavey, 1999b). The uncertainties expressed by women in this study reflect the information women desire when diagnosed with HPV, which should ideally be discussed with them prior to testing. These include high prevalence and the likelihood of spontaneous regression of HPV, that cervical cancer is slow to develop and that the subtypes of HPV associated with cervical cancer differ from those that cause genital warts (McCaffery and Irwig, 2005).

Within focus groups discussions, women raised concern about the potential stigma associated with being diagnosed with an abnormality. Some women believed that there was already limited disclosure about being diagnosed with cervical cancer

due to stigma, some referred to 'promiscuity', 'sleeping around' or not using condoms as risk factors and at times used language that placed the blame on women, particularly young women and their sexual behaviour. The avoidance of discourse about sexual activity, HPV and cervical cancer by health professionals has been found to perpetuate this uncertainty and potentially increases the stigma associated with cervical cancer as a disease associated with promiscuity. It was therefore recommended that clear messages need to be conveyed about the prevalence of HPV and that it is a very common outcome of sexual activity rather than the result of sexual impropriety (Waller et al., 2005; Braun and Gavey, 1999; Juraskova et al., 2011).

Women in focus group discussions expressed the need for increased community awareness about the risks and causes associated with cervical cancer and thought it was becoming more acceptable to talk about it openly, given other sensitive topics were more openly discussed, such as breast and prostate cancer. The desire for more open information about these issues has been found in other studies with the proviso that messages do not increase stigma but help normalise HPV (Waller et al., 2005; McCaffery et al., 2006; Brown et al., 2007; Kahn et al., 2007; McCaffery et al., 2003; Donders et al., 2009; Marlow, Waller and Wardle, 2007). Using a public health approach in messages about HPV that emphasises the high prevalence of the virus and how it is commonly found amongst sexually active adults has been suggested as an appropriate method to reduce stigma about HPV in the community (Friedman and Shepeard, 2007; Waller, McCaffery and Wardle, 2004a).

The primary finding in relation to perceived susceptibility amongst women in this study is that they are uncertain of the causes and risks of cervical cancer. Women in the focus groups talked about how they had been having Pap smears for many years without questioning why and some were surprised at how little they knew about what caused cervical cancer. Whilst knowledge alone is not thought to bring about behaviour change; perceived susceptibility to and the threat of cervical cancer is thought to be a precursor to participation in risk reduction activities and necessary for change to occur (Pitts and Phillips, 1998; Hancock et al., 1996; Rosenstock, 1974).

In light of these findings, which are well supported by previous reports in the literature, women need to be provided with accurate information about the causes

and risks of cervical cancer and the link between HPV, sexual activity and cervical cancer. Future studies should assess whether an increased range of information will lead to improved perceptions of women about their susceptibility to cervical cancer and in turn, the adoption of risk reduction strategies and preventative behaviours such as screening and vaccination, appropriate for their level of risk.

8.3 PERCEIVED SERIOUSNESS OF CERVICAL CANCER AND HPV

8.3.1 Perceived Severity of Cervical Cancer

Despite high levels of uncertainty about perceived susceptibility to cervical cancer, women participating in the focus groups were aware cervical cancer had serious consequences, which is consistent with the findings of other studies based on the HBM (Burak and Meyer, 1997; Jirojwong and Manderson, 2001; Baay et al., 2004). Whilst women's perception of cervical cancer as a serious disease is an important motivating factor for them to participate in cervical screening, there is also the risk that having too fatalistic a view towards cervical cancer may deter some women from participating in screening, especially if they believe the test is for the detection of cancer (Baay et al., 2004). In a study conducted in Belgium, the majority of women underestimated the chance of surviving cervical cancer. The authors concluded, that in the context of an organised program, accurate knowledge of the chance of survival may in fact prompt women to participate, if the fear of an abnormal result is lessened due to increased awareness that the result is likely to be preinvasive disease (Baay et al., 2004). Awareness of the purpose and meaning of the Pap smear therefore plays an important role within the context of perceived severity, as both a motivating factor or a potential barrier and is discussed further in the next section (Baay et al., 2004; Wardle, Pernet and Stephens, 1995).

8.3.2 Severity of Human Papillomavirus Infection

Women's perceptions about the severity of an HPV infection were found to be based on a number of misconceptions in both the CATI survey and focus groups. Their knowledge about the clearance of HPV without treatment was poor in the CATI survey (Table 8.1), and almost half the women surveyed believed antibiotics would cure HPV, suggesting as in other studies, confusion about whether cervical cancer is associated with a viral or bacterial infection (Kahn et al., 2003; Baay et al., 2004). Limited knowledge about the severity of HPV is also reflected in the

Victorian CATI survey in which 25% of women thought there was no cure for HPV and Kahn et al (2003), also reported only 32% of women thought HPV would go away with the right treatment (Pitts et al., 2007).

The misconception that HPV causes abnormal periods was consistent with the study from which the HPV knowledge scale was derived (Table 8.1), and slightly less commonly identified as causing problems in pregnancy (Kahn et al., 2003). The perception that HPV caused problems in pregnancy was also found amongst young women in which 72% believed HPV caused infertility and this belief was also expressed in some focus groups, for example, '*And it's just lurking in there waiting until you are 35 and are trying to have a baby and they say - sorry you've had HPV since you were 15 - sorry'* (Shand, Burney and Fletcher, 2010).

These misconceptions about the severity of HPV may have potential ramifications, especially if the age of commencement of screening is increased and HPV DNA testing becomes the primary screening test. If women are not appropriately informed about HPV and its largely transient nature, there may be subsequent alarm about potential changes to the National Cervical Screening Program (NCSP), given the concerns women have about its impact on reproductive health. There may be concerns if young women do not get screened until they are 25 years of age that they are being placed at risk, as many will not have yet started a family. A lack of understanding about the transient nature of HPV may also lead to increased alarm about a diagnosis of HPV, especially in light of the belief there was no cure. These misconceptions about the severity of HPV highlight the need to raise community awareness about the link between cervical cancer and HPV prior to changes to the NCSP.

8.4 PERCEIVED BENEFITS OF SCREENING AND VACCINATION

8.4.1 Screening

The findings of this study reveal some interesting nuances about women's perceptions and beliefs about the benefits of screening and in particular, Pap smears. When participants of both the CATI survey and the focus groups were asked, without prompting, about the purpose of the Pap smear, women's knowledge appeared high with most responding the purpose of the Pap smear was to detect abnormal cells. Fewer women in this study identified the test was to look for abnormal cells than

those reported by Giles and Garland (2006), who used a similar measure; however most of the women in their study were involved in clinical trials or being treated for abnormal Pap smear results. This suggests young women in their study may have been exposed to more information than women in the general community, and was reflected in the finding that none of the women in Giles and Garland's study (2006), indicated the Pap smear was a treatment for cervical cancer.

Another explanation for this difference may also relate to the method by which the survey was administered. Self-administered questionnaires with prompted responses were used, whereas women in this CATI survey were asked this question unprompted and could give multiple responses, which resulted in more response categories, such as *'general women's health'*. These responses were at times very broad, such as *'to see if something is wrong'* or *'prevent disease'*, and were similar to those found by Mays et al (2000) and Moreira (2006).

Only 40% of American adults identified the purpose of the Pap smear as the detection of changes in the cervix suggestive of precancerous or cancerous conditions when this specific terminology was used (Mays et al., 2000). In this study, it became evident that the meaning of the term 'abnormal cells' was a broad term that potentially incorporated more than precancerous cells and that more specific terms should be used in surveys. In the CATI survey, almost 50% of women indicated that an abnormal Pap smear meant there were abnormal or precancerous cells; however over one quarter of women thought an abnormal test most commonly meant cancer. This suggests many women perceive that cervical screening is for the early detection of cancer, like breast cancer screening, and not for precancerous changes which is similar to the findings of a Swedish study in which one third of women thought the main purpose of the Pap smear was to detect already developed cancer (Eaker, Adami and Sparen, 2001). It also helps explain why one quarter of women, as previously discussed, did not consider having regular Pap smears would reduce their risk of cervical cancer and why women in focus group discussions refuted that Pap smears were for preventing cervical cancer -'*You can't prevent it but you can find out...*'

High uncertainty about the purpose of the Pap smear has also been reported amongst American women and adolescents where over two thirds of the participants thought the Pap smear was synonymous with a pelvic examination (Blake, Weber

and Fletcher, 2004). In other studies, women often believed the Pap smear was for detecting other gynaecological cancers (Cooper, Polonec and Gelb, 2011; Hawkins et al., 2011; Mays et al., 2000; Eaker, Adami and Sparen, 2001; Shand, Burney and Fletcher, 2010). Confusion was also expressed by more than half the women in the CATI survey (Table 8.1), who thought the Pap smear was a test for HPV, which was slightly higher than the reported findings in a previous study (Kahn et al., 2003). This suggests that many women, despite extensive experience with cervical screening are unaware of the true benefits of Pap smears and as previously discussed, the perception of early detection versus the prevention of cervical cancer is a potential barrier for some women who fear the receipt of a cancer diagnosis.

Women's knowledge about the recommenced frequency for screening was found to be high, which is supported by the findings of a number of Australian studies (Shand, Burney and Fletcher, 2010; Giles and Garland, 2006). However, their knowledge and beliefs about other recommendations such as the age range of the eligible target population was limited. This was consistent with the finding in another Australian study conducted more than a decade ago, suggesting this belief has remained unchanged over time (Hancock et al., 1996).

Very few women knew Pap smears were not necessary for most women after a hysterectomy, although this was debated in the focus groups. These findings indicate low community awareness and misconceptions about the benefits of cervical screening within the context of an organised screening program amongst this well-screened population. As reported in Section 5.3.3, variation in cervical screening knowledge amongst women in the CATI survey was evident by screening status, although there were no independent predictors of cervical screening knowledge identified in a similar study conducted in the United Kingdom (UK) by Pitts and Clarke (2002). This suggests that women in the general population, who are unscreened and underscreened, may have even lower levels of knowledge than women in this study.

With proposed changes to the eligible population for cervical screening following the Renewal of the NCSP, concerns are likely to be raised given the limited understanding of the lack of benefits of screening for younger and older women amongst the participants in this study.

Most women participating in the focus groups believed the Pap smear was reliable although there was some concern that cancer could develop between tests, which supports the finding that women may be underestimating the time for precancerous changes to develop into cervical cancer. They were realistic about the effectiveness of the Pap smear and understood it was not 100% reliable, which they attributed to both laboratory issues and the provider's skill and that no test offered perfect protection, which was also found in an on-line sample involving young women aged 18–26 years by Shand et al (2010).

Misconceptions are common – even by women with extensive screening experience, including that Pap smears are an early detection strategy and do not prevent cervical cancer, and that young women and older women should be included in the eligible population despite the lack of benefit of screening for women aged less than 25 years and those over 70 years of age (IARC, 2005). Women also believed liquid-based cytology was superior to the conventional Pap smear, which was not confirmed when this technology was reviewed for inclusion in the NCSP (AHTAC, 1998). These misconceptions will need to be addressed prior to or while communicating any changes to the NCSP to ensure women understand the eligible age range and a potential change in screening test and schedule. This is particularly relevant if HPV DNA testing is introduced, given the interval between tests is most likely to be extended to five years for women with a negative result, as currently discussed (Meijer, 2011).

8.4.2 HPV Vaccination

High levels of awareness of the HPV vaccine were found in this study, 86% and 89% of women in the CATI survey and focus groups, respectively. This is consistent with other Australian studies conducted post vaccine implementation (Shand, Burney and Fletcher, 2010; Juraskova et al., 2011). High awareness of the vaccine has been attributed to widespread media attention surrounding the introduction of the vaccine when Professor Ian Frazer was named Queenslander and then Australian of the Year during the course of this study (Garland, Skinner and Brotherton, 2011b).

Lower awareness of the vaccine amongst women born overseas reflects previous findings among Victorian women born overseas, which led these authors to recommend specific strategies to ensure effective communication with women from

culturally diverse backgrounds (Pitts et al., 2007). A statistically significant difference in awareness of the vaccine by educational attainment was not found in this study, but was apparent in a Belgian study in 2007; however, this was overcome by an intensive mass media and education campaign (Donders et al., 2009). Women who had never had an abnormal Pap smear were also less aware of the vaccine, which could reflect their lower exposure to messages about cervical cancer than those with increased risk of disease, consistent with the findings by Giles and Garland (2006).

Table 8.2 Agreement with General Vaccination and HPV Vaccination Attitudes within the Current Study and Victorian CATI Survey

Attitude Item	**Current study**	**(Pitts et al., 2007)**
Vaccination in General	**%**	**%**
Prevention is better than cure for cervical cancer	96.2	97.7
Vaccines are an important way to prevent disease	96.4	97.6
Everyone should be vaccinated against preventable diseases in childhood	92.1	89.5
Vaccines that have been approved by the Health Department are safe	79.1	82.1
All children should be vaccinated against preventable conditions while they are still babies	86.5	79.9
The costs involved would influence my decision to have a child of mine vaccinated [a]	74.5	76.5
The convenience of the venue where the vaccine is given would influence my decision to have a child of mine vaccinated [a]	54.9	65.7
I worry about the side effects of vaccines for children [a]	41.1	51.6
HPV Vaccination		
If I had a 12 year old daughter I would not want her to be vaccinated against HPV [a, b]	89.1	n/a
Vaccinating young women and girls against HPV would encourage them to become sexually active [a]	87.2	90.6
If I had a 12 year old daughter I would need more information before I could decide whether she should be vaccinated against HPV	64.4	84.0
If I had a 12 year old daughter and my doctor thinks it is a good idea, I would have her vaccinated against HPV	86.2	83.8
There is more risk involved in being vaccinated than in having HPV [a, c]	81.5	79.6
The cervical cancer vaccine works best when it is given before a young woman becomes sexually active [b]	64.7	n/a

[a] These items were reverse scored i.e. participants disagreed with these items

[b] Different items measured - not directly comparable

[c] Positive item in Pitts et al (2007) study but comparable

In addition to high awareness, there was high acceptance of the vaccine amongst focus group participants and positive attitudes towards the vaccine expressed by women in the CATI survey, consistent with the findings of numerous studies both in Australia and overseas (Juraskova et al., 2011; McClelland and Liamputtong, 2006; Kahn et al., 2007; Marshall et al., 2007; Pitts et al., 2007; Cooper Robbins et al., 2010b; Dempsey et al., 2006; Gerend, Lee and Shepherd, 2007; Zimet et al., 2005b). CATI survey participants also had positive attitudes towards vaccination in general, although their attitudes towards the HPV vaccine were less positive, driven by high levels of uncertainty about some items in the HPV Vaccination Attitude Scale (Figure 5.9).

Attitudes of Victorian and Queensland women differed in three items (Table 8.2). Queensland women were more positive about vaccinating babies than their Victorian counterparts and more concerned about the side effects of vaccines for children. Queensland women were also more concerned about the convenience of the venue for vaccination, reflecting the geographically dispersed population in Queensland (CSSU, 2007c).

Women born in Australia were more likely to have positive attitudes towards HPV vaccination, which is consistent with the findings of the Victorian CATI survey (Pitts et al., 2007). Socio-economic status (SES) was a significant predictor in this study, with those living in the quintiles of most and least socio-economic disadvantage more positive towards the vaccine, but this was not a significant predictor in other studies, although different measures of SES were used (Brabin et al., 2006; Pitts et al., 2007; Marshall et al., 2007). As the vaccine is free in Australia and there were no differences in general vaccination attitudes observed by SES in this study, this finding warrants further exploration in the Australian setting.

More positive attitudes towards vaccination were also observed amongst women with a past history of an abnormal Pap smear, consistent with the findings of two American studies (Crosby et al., 2007; Dempsey et al., 2006; Zimet et al., 2005b). In these studies, experience with an abnormal Pap smear or a previous diagnosis of a sexually transmitted infection including genital warts, was found to impact on parents' perceptions of perceived benefits of the vaccine and susceptibility to HPV (Dempsey et al., 2006). However, screening status was not related to

vaccine acceptance amongst Mexican women aged 15–49 years (Lazcano-Ponce et al., 2001).

Cervical cancer/screening and HPV knowledge were also independent predictors of HPV vaccination attitudes and reflect the findings of other studies in which perceived benefits of vaccination and susceptibility to HPV were associated with vaccine intent (Juraskova et al., 2011; Kahn et al., 2003; McClelland and Liamputtong, 2006). Having heard of HPV was not associated with more positive attitudes towards vaccination; however awareness of the HPV vaccine prior to participating in the study was.

As expected, women with positive attitudes to vaccination in general were more likely to also have positive HPV vaccination attitudes, consistent with the Pitts et al, study (2007). Vaccine acceptance is considered essential for high levels of vaccine adherence and the positive attitudes expressed by women in this study reflect high community acceptance, which has been linked to relatively high levels of vaccine uptake in this country (Katz et al., 2010; Garland, Skinner and Brotherton, 2011b; National Immunisation Program, 2012).

The primary benefit of the HPV vaccine was seen to be the prevention of cervical cancer. Prevention against genital warts was not raised in focus group discussions, which could reflect poor media coverage of the dual protection offered by the quadrivalent vaccine used in the NHPVP (Cooper Robbins, Pang and Leask, 2011). The added benefit of protecting against genital warts was found to be a significant predictor of vaccination intent in a recent study of young women, who preferred a vaccine that had multiple benefits (Juraskova et al., 2011).

Uncertainty was also evident about who was most likely to benefit from vaccination with women unsure about the ages girls/women could be vaccinated for free, how many doses were recommended and whether the vaccine was prophylactic or therapeutic. There may be less confusion about eligibility now that the catch up programs for older women have ceased. Uncertainty about how the vaccine works and what it protects against was also found in a study of vaccinated school girls and their parents (Cooper Robbins et al., 2010a). Women in the present study acknowledged they often did not read vaccine information before consenting for their children's vaccinations, but did not judge themselves as critically as the mothers in the Cooper Robbins et al study (2010a), who referred to themselves as 'bad parents.'

Most women participating in the focus groups thought vaccinated young women should still have Pap smears, although there was some discussion about this amongst women, consistent with other studies conducted post implementation of the vaccine (Cooper Robbins et al., 2010a; Juraskova et al., 2011; Shand, Burney and Fletcher, 2010).

Despite high awareness and acceptance of the vaccine amongst women in this study, widespread uncertainty about the full benefits of the HPV vaccine is still present in the Australian context. Whilst current vaccination uptake is high, with 73% of 12–13 year old girls fully vaccinated in 2007–2009, increasing awareness of the benefits of vaccination may further improve vaccination uptake, especially the completion of the three course schedule (Garland, Skinner and Brotherton, 2011b).

8.5 PERCEIVED BARRIERS TO SCREENING AND VACCINATION

8.5.1 Screening

Despite regular participation in cervical screening, within the focus group discussions, women identified multiple barriers they face to Pap smears, many of which are cited in the literature, such as embarrassment, discomfort and the 'yucky factor' (Jirojwong and Manderson, 2001; Blomberg et al., 2008; Vanslyke et al., 2008; Van Til, MacQuarrie and Herbert, 2003; Fernbach, 2002; Orbell, 1996; Smith, French and Barry, 2003). These barriers suggest most women dislike Pap smears and find them embarrassing.

Cost was a barrier for women, particularly those from regional and lower SES areas, which was consistent with the findings of another Queensland study (Stewart and Thistlethwaite, 2010). Screening status however, did not differ by SES in a recent study, despite ecological evidence that Australian cervical screening participation and cervical cancer rates differ by SES (Smith et al., 2011; AIHW, 2011).

Access to services, particularly to a regular provider, was raised as a barrier by rural women and is consistent with the findings in other studies (Eaker, Adami and Sparen, 2001; Oscarsson, Wijma and Benzein, 2008; Wendt, Fridlund and Lidell, 2004; Van Til, MacQuarrie and Herbert, 2003). Other barriers described by women related to being time-poor and competing priorities, which are frequently described in the literature and relate to the multiple roles women have in modern day life

(Stewart and Thistlethwaite, 2010; Oscarsson, Wijma and Benzein, 2008; Smith, French and Barry, 2003; Waller et al., 2009; Waller et al., 2012; Kwok, White and Roydhouse, 2011). Increased flexibility in appointment times, services provided close to women and technological advances, such as SMS messaging appointment reminders, may play a role in facilitating women's attendance for screening, particularly young women (Waller et al., 2012).

Pelvic examinations are perceived by most women negatively and often times are described as invasive, degrading, embarrassing and uncomfortable (Waller et al., 2012; Wendt, Fridlund and Lidell, 2004; Smith, French and Barry, 2003; Orbell, 1996; Kwok, White and Roydhouse, 2011; Waller et al., 2009; Blomberg et al., 2008; Moore et al., 2000). Both physical and psychological factors may contribute to this.

Physical pain was caused by some providers described as 'rough', irrespective of gender, and the cold metal speculum and 'scraping' feeling when cells were being collected from the cervix were perceived as painful by some women, also described previously in a number of studies (Burak and Meyer, 1997; Kwok, White and Roydhouse, 2011; Orbell, 1996; Waller et al., 2009; Waller et al., 2012). Of note is that perceived pain has been found to differ between women by screening status, with women less likely to screen more likely to perceive the procedure as painful (Burak and Meyer, 1997).

Psychological discomfort included feeling vulnerable, *('legs in the air')* or perceiving the procedure as an invasion of privacy (Oscarsson, Wijma and Benzein, 2008; Kwok, White and Roydhouse, 2011; Wijma and Siwe, 2004; Waller et al., 2012; Blomberg et al., 2008). In addition to previously described barriers, insight into the concept of embarrassment was revealed through the focus groups. Embarrassment is commonly identified by local and international studies, irrespective of age (Alder and Foxwell, 1999; Waller et al., 2009; Waller et al., 2012; Orbell, 1996; Kwok, White and Roydhouse, 2011; Smith, French and Barry, 2003; Van Til, MacQuarrie and Herbert, 2003; Burak and Meyer, 1997; Moore et al., 2000) and was related to issues, such as women having to expose themselves (modesty), whether they were clean, issues about intimacy and concern about the provider being embarrassed.

Modesty is raised in a number of studies, including a study of Chinese Australian women (Kwok, White and Roydhouse, 2011). In other studies, women also expressed concern about exposing private parts of their bodies, especially if they had suffered prior physical or sexual abuse (Oscarsson, Wijma and Benzein, 2008; Blomberg et al., 2008; Smith, French and Barry, 2003). Negative body image has also been raised as a barrier in other studies (Fagan et al., 2011; Waller et al., 2012), particularly obesity, but not this study, with the exception of one comment -*"Or they are going to see your rolls of fat?"*

The role of a chaperone present during the Pap smear procedure was ambiguous, with some women seeing this as an important option, particularly if their regular doctor is unavailable or the provider is male; however, many prefer privacy for pelvic examinations and do not wish a chaperone to be present, particularly when this is the receptionist (Khan and Kirkman, 2000; Baker et al., 2007).

An unexpected and new barrier identified in this study was related to intimacy, in terms of women viewing their body as part of their sexual being and feeling uncomfortable exposing themselves and being touched by someone other than their partner. A number of Swedish papers discuss how pelvic examinations potentially blur the boundaries between the public and private spheres in a woman's life and how the interaction between the woman and the examiner results in both parties cognitively restructuring and defining a situation that would normally be sexual in nature, to that of a medical investigation (Wijma and Siwe, 2004; Oscarsson, Wijma and Benzein, 2008; Blomberg et al., 2008). In previous studies, intimacy was not always discussed in the same context as it was in this study, whereby some women described how the procedure could potentially compromise a relationship, for example, "*I actually think a lot of women sort of hold back because it's the actual thought – well it's not my husband looking down on there – it's someone strange so you're actually going to see and you're sort of thinking well it's not going to be private anymore"* or *"Well it is very personal isn't it, for a woman, and I only do that with my husband, you know I don't look at the doctor as my husband"*.

For some women though, this was discussed as a control issue where men were perceived to prevent their partners having these procedures. Partner violence has been identified as a predictor of lower cervical screening uptake amongst middle

aged Australian women, and a later stage of cancer diagnosis in an American study (Loxton et al., 2009; Modesitt et al., 2006).

Fear and denial was also discussed in the focus groups and has been identified in other studies (Smith, French and Barry, 2003; Oscarsson, Wijma and Benzein, 2008; Waller et al., 2009). Denial as a barrier was raised primarily by older women who assumed young women did not perceive themselves to be at risk of cervical cancer, which was consistent with health professionals' perceptions of why young women's cervical screening participation rates were declining in the UK (Waller et al., 2012). There is evidence suggesting young women do not perceive themselves to be at high risk of cervical cancer or HPV in a number of studies or have become apathetic towards cervical screening, which highlights the need for accurate perceptions of risk (Baer, Allen and Braun, 2000; Burak and Meyer, 1997; Waller et al., 2012).

In this study as in others, a prior negative experience, whether physically or psychologically unpleasant, is a commonly cited barrier (Smith, French and Barry, 2003; Waller et al., 2012; Waller et al., 2009; Blomberg et al., 2008).

Despite an extensive number of barriers, most women reported they attended regularly for a Pap smear, which may be associated with personal moral obligation. Personal moral obligation suggests women comply with screening recommendations because they perceive it to be socially desirable or following the recommendation of their general practitioner (GP) or health authority, and has not been included in existing health behaviour models but should be explored in future studies (Tacken et al., 2007; Orbell, 1996).

Increased efforts are needed to promote participation if the gains witnessed in Australia are to be maintained and if unvaccinated women, in particular, are to be afforded the protection of the NCSP in the future. With the Renewal of the NCSP, the primary test may change, however, the method by which it is collected is similar to that of the Pap smear and will be no less embarrassing. The Renewal does offer the opportunity though, to address cost as a barrier, investigate the feasibility of self collection for women who do not currently participate in the NCSP and introduce a less intensive screening program, whereby women are required to undergo this unpleasant procedure much less frequently. It also provides the opportunity for the educational preparation of Pap smear providers to be reviewed and for quality

standards in training and competency to be standardised across health disciplines. These opportunities may assist in addressing the barriers described by women in this study to optimise women's participation in the NCSP in the future.

8.5.2 HPV Vaccination

Relatively few barriers or concerns were raised by women about vaccination, and mainly related to the vaccine being new with little long-term effectiveness data, and concerns about side effects of vaccines in general (Shand, Burney and Fletcher, 2010; Juraskova et al., 2011; Marshall et al., 2007; Rosenthal et al., 2007). This may reflect media coverage in which the Government was accused of using Australian girls as guinea pigs, despite the evidence from extensive clinical trials that demonstrated the safety of the vaccine (Garland, 2007b; Cooper Robbins, Pang and Leask, 2011; Koutsky and Harper, 2006).

Concern about vaccinating girls against a sexually transmitted infection was not found to be a barrier in this and other Australian studies, although the attitudes of culturally diverse Australians are not widely represented in existing research (Juraskova et al., 2011; Cooper Robbins et al., 2010b; Cooper Robbins et al., 2010a; Shand, Burney and Fletcher, 2010; Marshall et al., 2007). In more conservative countries, such as the USA, parental surveys showed concern that the vaccine may promote sexual activity in young girls (Olshen et al., 2005; Krishnan, 2008; Zimet et al., 2005b; Brabin et al., 2006). For Australian parents, how to discuss the association between HPV as a sexually transmitted infection was seen as a challenge by some (Cooper Robbins et al., 2010b).

8.6 CUES TO ACTION

Within the focus group discussions, women provided extensive insight into cues to action for both screening and vaccination and strategies for communicating changes following the Renewal of the NCSP.

8.6.1 Enablers to Cervical Screening Including Self Collection

Education of young women in schools was one strategy to help normalise cervical screening as an activity women engage in to keep healthy and was previously identified as a motivating factor for having had a Pap smear in a study of American college students (Burak and Meyer, 1997). The importance of reminder

systems, such as a letter from a health professional or the Pap Smear Register (PSR), was raised as a preference to opportunistic screening where the examination was sprung upon women when attending a GP for an unrelated issue and they had no time to prepare or as one woman said *'wear your good undies'*. This is particularly relevant in the Queensland context where the temperature in summer can reach more than 40^{o} Celsius. Reminder systems and invitation letters have been found to be effective cues to action that prompt women to participate in screening, although in a Swedish study, Blomberg et al (2008), found some women interviewed thought an invitation letter from the government was coercive and akin to a 'Big Brother' approach to healthcare (Kwok, White and Roydhouse, 2011; Smith, French and Barry, 2003; Day, van Dort and Tay-Teo, 2010). Paternalism was also identified in a recent study in which health staff, such as practice nurses and GPs, described coercive attitudes towards encouraging women to participate in cervical screening, especially where GP incentives were in place (Waller et al., 2012).

Women discussed strategies they thought providers could adopt that would reduce discomfort and embarrassment during the Pap smear procedure, although these were somewhat individualised and at times contradictory, for example, some women wanted the provider to explain what they were doing, whilst others wanted them to talk about something else or did not want to think about it and tried to block out what was happening 'down there'. The importance of explaining the procedure as it was being conducted was deemed important by 95% of women in an Australian study of women's views about intimate examinations and was closely linked with women's perceptions of comfort and trust during the procedure (Moore et al., 2000).

A consistent theme from focus group discussions, often irrespective of the provider's gender, was that women wanted a skilled practitioner they could trust, which has been found in other studies (Moore et al., 2000; Blomberg et al., 2008). The establishment of trust and describing the procedure before, during and afterwards has been described as important in creating confidence, being engaged and respectful towards the woman and essential if the woman is to be an active participant in the process (Wendt, Fridlund and Lidell, 2004; Stewart and Thistlethwaite, 2010).

Women also supported the role of nurse Pap smear providers and often talked about the Mobile Women's Health Service or their local practice nurse which reflects

the acceptability of nurse Pap smear providers found in the literature (Christie, Gamble and Creedy, 2005; Victorian Cervical Cytology Registry, 2012). The 'one stop shop' concept was raised as an enabler in a number of focus groups, where women could have their breastscreen and Pap smear at one visit.

Women in the focus groups were supportive of a hypothetical self collected test; however raised concerns about the safety and efficacy of self testing and worried they may not do the test properly or contaminate the specimen. Similar concerns were also reported in a study where women's comfort with self collection was lower compared to a physician collected sample, attributed to women's concerns about whether they had done the test properly (Quincy, Turbow and Dabinett, 2012). However, in a UK study, women attending for a Pap smear were provided with a kit containing written instructions for a HPV DNA self collected sample and no other information. More than 90% of women felt confident they had done the test properly and over 70% indicated a preference for doing a test at home in the future, if it were offered, rather than having a clinician administered test, although cultural differences were observed in acceptability (Waller et al., 2006).

Women in the focus groups felt self collection was a good option for underscreened women, provided the test had clear instructions, and although most women reported regular participation in screening, some comments indicated women who did not participate regularly would consider this option – '*From my point of view I wouldn't have gone so long without it if I had something like that'*. Self collection was not supported as a replacement to health provider collected samples by women in this study, but was considered a viable option for those women who could not overcome their embarrassment to have a Pap smear.

8.6.2 Sources of Information

Although most women said they had heard about the HPV vaccine through mass media, particularly television, health professionals were frequently cited as sources of HPV vaccine awareness, which is similar to the sources described elsewhere (Juraskova et al., 2011; Rosenthal et al., 2007). Women in the Victorian CATI survey also identified mass media as the primary source of awareness of HPV (Pitts et al., 2007). The influence of mass media on community knowledge was measured in an American study in which those exposed to health media were found to be more likely to learn about the cause of cervical cancer following increased

media coverage post approval of the HPV vaccine by the Food and Drug Administration (Kelly et al., 2009). Mass media strategies have been found be an effective strategy for increasing screening participation; however one-off media campaigns do not result in sustained increases over time (Day, van Dort and Tay-Teo, 2010).

Health professionals were also considered to be reliable sources of health information amongst women in the focus groups and pharmacists were included amongst this group. In the limited research about health professionals' knowledge and attitudes to HPV vaccination in the Australian setting, GPs and gynaecologists were found to be positive about HPV vaccination and perceive their knowledge to be high; however self rated knowledge about HPV and the vaccine was found to be considerably higher than measured knowledge amongst GPs (Brotherton, Leask, et al., 2010; Tan, Farrell and Allen, 2010; Leask et al., 2009). Women's health nurses and Aboriginal and Torres Strait Islander health workers have also been found to support the benefits of the HPV vaccine and in a Victorian focus group, demonstrated good knowledge and considered they were well placed to educate women about HPV (Leask et al., 2009; Rosenthal et al., 2007).

The capacity of Australian pharmacists to provide women with information about HPV test results has been questioned; however in other countries their role in infection prevention through vaccination, including HPV vaccination, has been recognised (Blank, 2009; Woodford Guegan, 2010). School was identified as a source of awareness of the HPV vaccine and identified in focus groups as a good source of information. The role of teachers and school staff has been found to be important for uptake of vaccination and the need to educate teachers about HPV and the vaccine has been identified in the literature (Cooper Robbins et al., 2010c; Garland, Skinner and Brotherton, 2011b). These findings suggest health professionals including pharmacists, and teachers are important sources of information and therefore need to be supported in this role.

Word-of-mouth and family and friends were frequent sources of awareness of the HPV vaccine in the CATI survey, which is a consistent finding in other studies (Pitts et al., 2007; Rosenthal et al., 2007). Women also found having guest presenters at their meetings beneficial, especially if the speaker had a high profile, for example, some had attended a session with Professor Ian Frazer. This study

highlights the role women's organisations play in disseminating information through their regular networks and peer support. Community interventions have been found to have a positive impact on knowledge and screening participation at the local level, although are not associated with increasing participation rates at the population level (Day, van Dort and Tay-Teo, 2010).

Web-based information was not highly utilised by women in the focus groups and was not a frequent source of HPV awareness at the time the study was conducted; however this may be due to age profile of participants as the average age of women was 55 years. There has been increased usage of the Internet in general society over time and reported use of the Internet as a source of information by women following a positive HPV DNA test (Livesley, 2010; McCaffery and Irwig, 2005). As evident in both the CATI survey and focus groups, women obtain health information from a number of sources, therefore it is important to develop communication strategies that utilise a number of approaches for the broad age range of women eligible for cervical screening.

8.6.3 New Technologies

With the renewal of the NCSP, there is a real possibility HPV DNA testing may be introduced either as a primary screening test or as part of alternative screening pathways in a cytology-based program. Liquid-based cytology is likely to be introduced in conjunction with HPV DNA testing and women will therefore be offered alternative tests to the Pap smear. Women, when asked what they would need to know to trust any new test introduced into the NCSP, wanted to be assured the test was as safe and as reliable as the Pap smear. In preference studies, women who were informed about the benefits of HPV DNA testing compared to the Pap smear chose the former given its higher sensitivity (Brown et al., 2007; Huang et al., 2008).

Trust and safety issues also apply to extending the screening interval or changing the age range for screening as many women in the CATI survey perceived the Pap smear to be for the early detection of cervical cancer and some raised concerns that a two yearly screening interval was risky, as they perceived cancer could develop in the intervening period. In a study of older ethnically diverse women aged 50–80 years, women were not willing to have Pap smears less often, even if their HPV DNA test was negative and their physician recommended it

(Huang et al., 2008). In addition, nearly two thirds of women wanted between two and four Pap smears per year if they received a positive HPV DNA test result (Huang et al., 2008). These findings indicate the importance of increasing community knowledge and awareness about HPV and the benefits of HPV DNA testing, prior to the introduction of changes to the current NCSP, to ensure women trust that any new recommendations will not place them at harm.

The information women wanted to know about the HPV vaccine also highlights that safety is at the forefront of women's minds and is consistent with the findings of focus groups conducted prior to the implementation of the NHPVP (Rosenthal et al., 2007). Women also felt more information should be available about the risks of vaccination versus contracting HPV, how effective the vaccine was and what the risk of cancer was for a girl who was not vaccinated, which were issues identified in a study of vaccinated girls and their parents (Cooper Robbins et al., 2010a). Widespread information should be considered, as although mothers commonly provide consent for the vaccine or discuss it with their daughters, fathers who have more information may be better placed to support their children in decision-making about the vaccine, which will be increasingly important with the recent inclusion of HPV vaccination in the NHPVP for boys (Cooper Robbins et al., 2010b; Katz et al., 2010).

8.6.4 Recommended Methods for Communication Strategies

The recommendations women in the focus groups made for disseminating new information about cervical cancer prevention provide insight into what women perceive are effective methods in their communities. This discussion was framed in terms of communicating changes to the NCSP and did not explore issues associated with HPV as a sexually transmitted infection, which has been discussed in existing studies (Friedman and Shepeard, 2007; Rosenthal et al., 2007; Waller, Marlow and Wardle, 2007; Szarewski, 2011; Smith et al., 2011).

Women supported sending a letter to all women registered on the Queensland Health PSR, provided it was appropriately branded and contained concise information that would grab their attention, whilst cautioning about the limitations of this method as unscreened women would not receive it. Whilst mass mail outs via the PSR results in a high volume of return to sender mail, increases in phone calls to the register and cervical screening participation rates suggest this is an effective

strategy for reaching many women (Queensland Cervical Screening Program, 2012; Morrell et al., 2005).

Women in the focus groups suggested multiple strategies and methods to ensure women with diverse needs have access to information, which has been identified in previous studies (Kirk et al., 1998; Rosenthal et al., 2007; Wollin and Elder, 2003; Pitts et al., 2007; Webster, 2007; Leask et al., 2009; Jirojwong and Manderson, 2001). The limitations associated with mass media were raised by women in the focus groups and reflect those identified in content analyses of newspaper and television articles; however, content in television programs or talk back shows with a relevant expert was thought to be effective. This was observed in the UK when cervical screening participation rates increased after the fictional death of a main character in a popular television soap opera, Coronation Street, and after a young women, Jade Goody, who appeared on a reality television show, Big Brother, died from cervical cancer (Cooper Robbins, Pang and Leask, 2011; Kelly et al., 2009; Howe, Owen-Smith and Richardson, 2002; Bowring and Walker, 2010).

Women in the focus groups spoke of other novel strategies for disseminating information that were linked to social marketing and require further investigation, piloting and evaluation to determine their effectiveness. The cues to action described by women in this study provide extensive insight into what motivates them to participate in screening, such as provider recommendations and reminder letters, and where they obtain health information that they trust. They considered cervical cancer to have low prominence in the community, especially compared to other cancers and that more information should be readily available to increase women's knowledge about cancer, screening and vaccination.

The findings of this study have been described in this chapter as they relate to the HBM and are summarised in the final section.

8.7 THE HEALTH BELIEF MODEL

The HBM provided an ideal framework for exploring what women know and say about cervical cancer/screening, HPV, the HPV vaccine and their attitudes towards Pap smears and is presented in Table 8.3.

Utilising this theoretical framework revealed that despite extensive experience with screening, the women in this study had misconceptions and knowledge gaps

directly related to their perceived susceptibility to cervical cancer due to high levels of uncertainty about the causes and risks of cervical cancer, including HPV.

Self-efficacy and taking control over one's own health was reflected in women's statements about what causes good health, but also highlighted how common misconceptions, for example, that cervical cancer runs in families, impacts upon women's sense that preventing cervical cancer is within their locus of control. With decreased incidence of cervical cancer in the Australian setting, few women will have a relative with cervical cancer and therefore may wrongly perceive they are not at risk of cervical cancer and do not need to participate (AIHW, 2011).

Low perception of risk due to poor knowledge has been identified as a potential barrier to participation in both cervical screening and HPV vaccination programs, although knowledge is not always a reliable predictor of behaviour and should be viewed in the context of other factors (Braun and Gavey, 1999; Waller et al., 2009; Waller et al., 2012; Baileff, 2000; Burak and Meyer, 1997; Jirojwong and Manderson, 2001; McClelland and Liamputtong, 2006). Lack of knowledge about HPV and its link with cervical cancer may present a significant barrier to women's acceptance of changes to the NCSP if HPV DNA testing is introduced as part of the screening pathway, as research has found significant psychological distress results from a positive HPV diagnosis when women have limited knowledge of these issues (Maissi et al., 2004; McCaffery et al., 2006). This distress has been found to be time-limited and to decrease with the provision of accurate information, and demonstrates the need to increase community awareness about HPV (Maissi et al., 2005).

The HBM also provided insight into how limited community awareness and personal experience with cervical cancer impacted upon women's perceived susceptibility to disease. Despite limited exposure to women with cervical cancer, women still perceived cervical cancer to be a serious disease that had serious consequences if not detected early, which is a consistent finding in other research (Burak and Meyer, 1997; Baay et al., 2004). Women also had misconceptions about the seriousness of HPV as an infection, which could potentially lead to unnecessary anxiety about a positive diagnosis, including concerns about infertility and a lack of awareness of the transient nature of infection amongst most women.

Exploration of the perceived benefits of cervical screening in this study revealed that despite extensive experience with cervical screening many women did not know the true benefit of Pap smears as a prevention strategy for cervical cancer, which has been attributed in the literature to result from providers' assumptions that women who attend regularly for screening have adequate knowledge about the screening program (Szarewski, 2011). The notion that Pap smears were for the early detection of cancer presents a potential barrier for women who fear receiving a cancer diagnosis and who have a fatalistic view that cervical cancer is untreatable and is worse than breast cancer (Baay et al., 2004; Jirojwong and Manderson, 2001; Chavez et al., 1997).

This study also highlights the benefits of HPV vaccination are not well understood, with uncertainty expressed about the effectiveness of the vaccine and little reference to it as a preventative against genital warts.

The barriers to Pap smears women described in focus group discussions are consistent with those described in other studies, although the concept of embarrassment was described in greater detail. These barriers will persist irrespective of the screening test used in the NCSP as the collection method is the same unless self testing is provided as an option for women who continue to be unscreened and may be the most effective cue to action for these women (Sanner et al., 2009).

Enquiring about cues to action for screening also highlighted women's compliance with their health providers' recommendations about cervical screening including paying to have additional tests despite not fully understanding the role of these tests or being able to name them and in most instances, disliking the test intensely.

Women provided extensive insight into cues to action for screening and vaccination, such as providers' recommendations and reminder systems. The role of providers as a trusted source of advice was raised in focus groups and influenced some women's decisions about having the vaccine. Some women questioned why they put so much faith in the medical profession whilst others trusted the vaccine because it would not be supported by doctors unless it was safe.

Table 8.3: Relationship of Research Questions and Study Findings to HBM

Research Questions	HBM FACTORS	FINDINGS
What do women know about cervical cancer/screening and what are their attitudes towards Pap smears?	Self-efficacy	Self management
		Aspect of luck related to genetics
		Potential external locus of control given high level of response that genetics or family history is associated with increased risk of cervical cancer in both CATI survey and focus groups
	Perceived susceptibility to disease	Potential for not considering susceptible or a threat due to high uncertainty in focus groups re cause
		Family history most common cause in CATI survey
		HPV identified but uncertainty high in CATI survey
		Potential for not considering at risk due to high uncertainty about the links between cervical cancer, HPV and sexual activity including behaviours that are known to increase risk in both CATI survey and focus groups
		Smoking not considered a risk factor by 28% of women in CATI and women in focus groups nor high parity or OCP
		Hygiene considered a risk factor by more than half of participants
		Sexual behaviours linked with 'promiscuity' in both studies that potentially could leave some women not perceiving themselves to be at risk
	Perceived seriousness of disease	Perceived cervical cancer to be serious
		Some indication of fatalistic view that was impacted by view that Pap smears detect cervical cancer as opposed to secondary prevention
		Early detection decreased impact
		Overall low community awareness or experience with cervical cancer
	Perceived benefits of taking action	Perceived benefits impacted by perception that NCSP was an early detection program – 19% thought it was a treatment of cancer; 27% of women in CATI saw this as an early detection program
		CATI survey did not reveal this as 'abnormal cells' was assumed to be a correct response; however in the focus groups this was revealed to be interpreted by many as abnormal cancer cells not precancerous abnormalities

Research Questions	HBM FACTORS	FINDINGS
		Poor knowledge of the current NSCP target age group
	Perceived barriers to action	Multiple barriers identified and explored in-depth although given women's experience with Pap smears these did not prevent many women from attending
	Cues to action	Identified enablers/cues to action to reduce embarrassment
		Women were receptive to an alternative option provided concerns were addressed and thought this may encourage women who did not have Pap smears to participate in screening
What do Queensland women know about HPV and what are their attitudes towards the cervical cancer/HPV vaccine?	Perceived susceptibility to disease	Perceived susceptibility potentially low given high levels of uncertainty in both CATI survey and focus groups and the link with sexual activity and sex-related risk factors poorly understood, i.e. if not 'promiscuous' not at risk
	Perceived seriousness of disease	HPV was thought to have serious implications for fertility and menstrual problems
		Low awareness HPV could resolve spontaneously
	Perceived benefits	Perceived benefits not well understood due to uncertainty about the vaccine and whether it was prophylactic or therapeutic and the risks associated with not being vaccinated; however high levels of acceptance
		No mention of benefit of protection against genital warts
	Cues to action	More information required about side effects, safety efficacy, benefits and how it works
What do they women perceive as the most effective methods of communicating and promoting new information should changes be made to the NCSP	Cues to action	Mass media most common source of information although not always considered a reliable source
		Health professionals including pharmacists considered a trusted source of information Recommended multiple and novel strategies to ensure diversity of women in target age group reached through communication strategies

CATI surveys in recent times, similar to that used in Phase 1 of this study, have explored knowledge about cervical cancer/screening, HPV and attitudes towards the HPV vaccine; however Phase 2 of this study added an extra dimension by providing insight into women's beliefs about HPV and the HPV vaccine and exploring the links between knowledge, attitudes and beliefs as this can identify misconceptions or knowledge gaps that are not explicit when fragments of knowledge are assessed (Brown et al., 2007).

The HBM also provided a rich source of information about cues to action should a new test be introduced, ways to encourage parents to consent for their daughter to be vaccinated and how to communicate changes to the NCSP following the Renewal of the Program. The use of the HBM in this study enabled the exploration of knowledge, attitudes, beliefs and experiences that were not possible through the CATI survey alone and confirmed the relevance of this model in understanding women's perceptions of primary and secondary prevention strategies.

The conclusions drawn from this research are described in the next chapter.

Chapter 9: Conclusions

This study provides unique insight into the beliefs underpinning Queensland women's knowledge about the causes of and associated risks for cervical cancer, their perceptions about cervical screening and human papillomavirus (HPV) and their concerns about the HPV vaccine. This thesis has described the literature surrounding cervical cancer/screening, HPV and the HPV vaccine and women's knowledge of these concepts, their attitudes towards Pap smears and vaccination, the rationale and methods used to explore the key research questions and the findings of this study and their place within existing research. This final chapter provides an overview of the conclusions drawn from this study (Section 9.1), the strengths of the study (Section 9.2), its limitations (Section 9.3) and finally the recommendations resulting from this research (Section 9.4).

9.1 CONCLUSIONS

This study reveals that Queensland women have insufficient knowledge about the causes and risks of cervical cancer on which to accurately determine their perceived susceptibility to this disease. There was considerable uncertainty about the link between cervical cancer, HPV and sexual activity amongst women in this study. Women had limited knowledge about their susceptibility to HPV and the severity of it as an infection, despite most (over 60%), having heard of it prior to the study. Women also had limited understanding of the benefits of screening as a prevention strategy, with many women thinking the purpose of the Pap smear was for the early detection of cancer, and considerable uncertainty about the benefits of the HPV vaccine. Despite high awareness of the vaccine (over 86%), women were uncertain about the number of doses, whether the vaccine was therapeutic or prophylactic and in the focus groups, did not discuss or acknowledge that the HPV vaccine could also prevent genital warts.

Women in this study described extensive barriers they experience when participating in cervical screening and provided in-depth insight into the physical and psychological discomfort they experience when having Pap smears. The most

common barriers to vaccination were concern about side effects and a lack of information upon which to make a decision about consent.

Women described cues to action, including enablers for screening participation, such as reminder systems and practitioner characteristics, and expressed positive views towards self collected testing, particularly for women who did not attend screening. They also provided extensive insight into their information needs about HPV vaccination and other new technologies, such as HPV DNA testing, that may be introduced into the National Cervical Screening Program (NCSP) following the Renewal. This information is most relevant for promoting the benefits and addressing some barriers related to these new technologies, including concerns about potential side effects or safety issues. Women also provided recommendations and innovative strategies for disseminating new information about changes to the NCSP to inform future communication strategies in Queensland.

The only significant predictor of cervical cancer/screening knowledge was screening status with underscreened women having lower knowledge than regular/overscreened women. Above average cervical cancer/screening knowledge was associated with above average HPV knowledge, having heard of and having positive attitudes towards the HPV vaccine.

HPV awareness and knowledge differed by age and was higher in younger women. Women who had no post-school qualifications, were not married and had never had an abnormal Pap smear, had lower odds of having heard of HPV. Marital status was a significant predictor of HPV knowledge with lower knowledge observed in married women and those in defacto relationships relative to those who had never married. Above average HPV knowledge was also associated with high awareness and positive attitudes towards the HPV vaccination. Women aged over 60 years and those aged 30 to 39 years of age were at lower odds of having heard of the HPV vaccine than younger women, as were women born overseas and those had completed less than Year 10 at school. Women who had never had an abnormal Pap smear were also at lower odds of having heard of the HPV vaccine than those who had.

High acceptance of the HPV vaccine was found amongst women in this study, although women's knowledge deficits impacted on their perception of the benefits of vaccination, as predictors of positive attitudes were above average cervical

cancer/screening and HPV knowledge. Women born overseas and those living in average areas of socio-economic well-being had less positive attitudes than those in the highest and lowest areas of socio-economic disadvantage. Having had an abnormal Pap smear was a significant predictor of a positive attitude towards the HPV vaccine as was being positive about vaccination in general.

This study reveals significant gaps in Queensland women's knowledge that require innovative and effective communication strategies to address. Failure to increase women's knowledge about cancer prevention strategies will impact upon their perceived beliefs about cervical cancer and HPV including their perceptions of risk and susceptibility, their views about the benefits of screening and HPV vaccination and may ultimately impact upon their acceptance of changes and participation in the NCSP.

The use of mixed methods enabled the exploration of knowledge and attitudes by socio-demographic factors and screening history through the CATI survey, the findings of which were explored further in the focus groups, and found to be consistent. The Health Belief Model (HBM) enabled the exploration of knowledge, attitudes, beliefs and experiences that were not possible through the CATI survey alone and confirmed the relevance of this model in understanding women's perceptions of primary and secondary prevention strategies. The findings of this study and their relationship to the HBM utilising a framework developed by Waller et al (2012) is demonstrated in Figure 9.1.

This model includes an additional construct to the original HBM, intention formation, as failure to consider this when assessing health behaviours has been identified as a limitation of the HBM (Sheeran and Orbell, 2000). The findings of this study have contributed to understandings about factors relevant to individual perceptions, modifying factors, intention formation and action within this model. This study has therefore contributed to the knowledge about these factors in accordance with its aim to describe and explore what Queensland women know and say about cervical cancer/screening, HPV, Pap smears and the HPV vaccine. Despite not aiming to assess intention to participate in screening, this study has also contributed somewhat to intention formation as described by Waller et al (2012) in this model, that is worth exploring further in future studies.

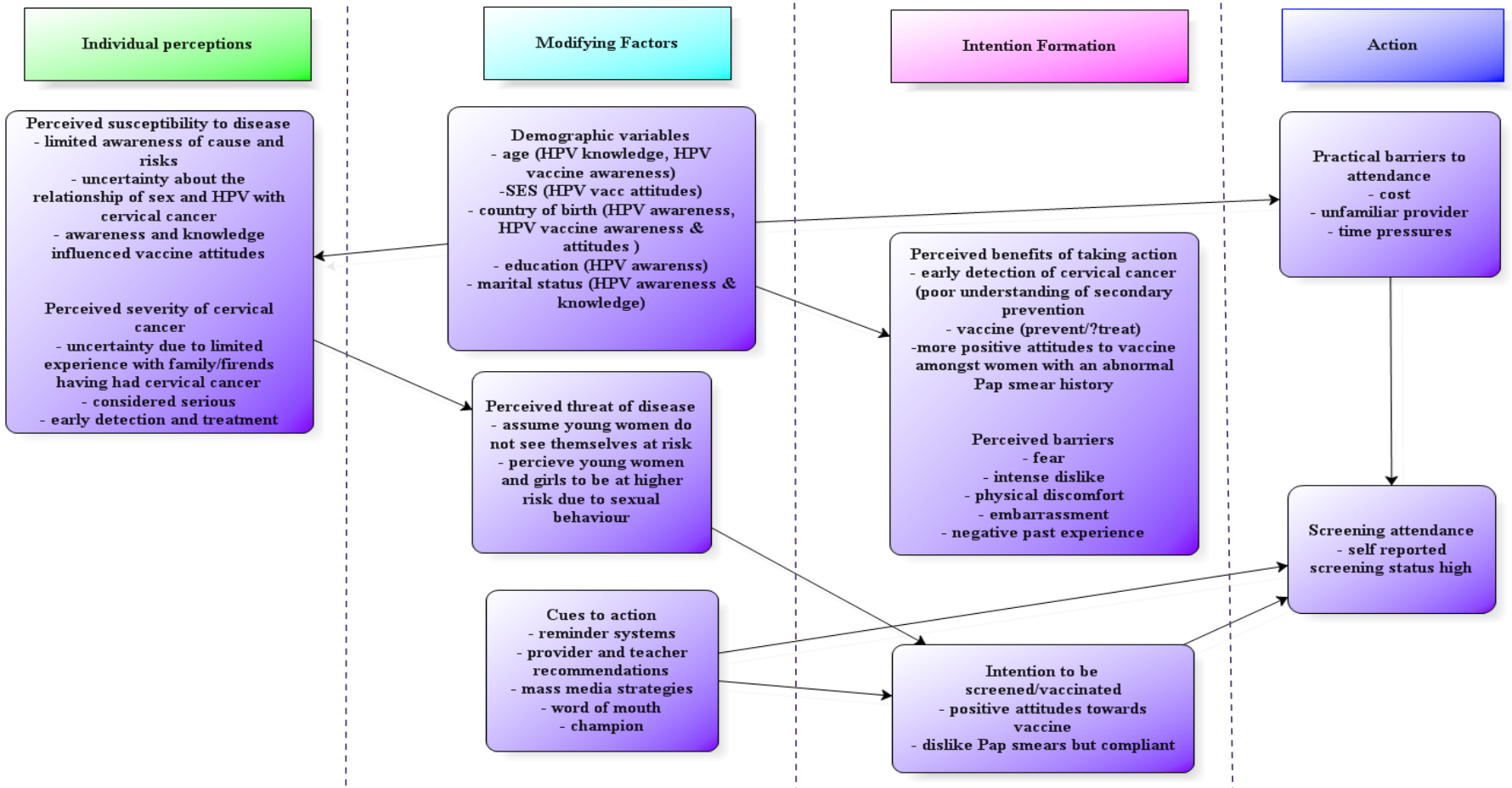

Figure 9.1 Factors Influencing the Impact of Primary and Secondary Prevention Strategies for Cervical Cancer among Queensland Women

(adapted from Waller et al, (2012)

The strengths of this study and the contribution it makes to the body of knowledge about cervical cancer prevention are described further in the next section.

9.2 STRENGTHS

This study is the first large study about HPV knowledge and vaccine attitudes conducted in Queensland that has used a mixed methods approach and a largely representative sample of women. It is also the first large study to explore women's perceptions of the Pap smear and barriers to screening across a range of locations and areas of differing socio-economic disadvantage in a state that consistently reports differences in cervical screening uptake by rurality and socio-economic status (SES) (QCSP, 2012). The inclusion of women from more regional and remote areas identified minimal impact of locality on knowledge and attitudes amongst women surveyed but provided insight into specific issues impacting on rural women who face different challenges and barriers than their city counterparts. The oversampling by women from areas of socio-economic disadvantage in the CATI survey also enabled exploration of knowledge and attitudes by socioeconomic status and demonstrated limited impact of SES on these factors. In the focus groups, the cost of screening was raised as a barrier by women living in areas of lower SES, suggesting this may be one contributing factor that impacts on their participation in screening.

The HBM provided a useful framework to explore knowledge, beliefs and attitudes to screening and vaccination and highlighted considerable uncertainty about many aspects of cervical cancer and primary and secondary prevention strategies available in the Australian setting, which need to be considered in the context of anticipated changes to the NCSP over the next few years.

The study has also highlighted that community perceptions about the NCSP are often inaccurate(AIHW, 2011)(AIHW, 2011)(AIHW, 2011)(AIHW, 2011)(AIHW, 2011). Although the NCSP has recently celebrated its 20 year anniversary, many women view the role of Pap smears as an early detection strategy and not a method of prevention. The incorporation of qualitative research has also contributed to greater understanding as to what influences women's beliefs and the misconceptions women have about when women should start and cease screening. It also highlights the limitations in quantitative measures for assessing women's knowledge about the

purpose of Pap smears and the meaning of an abnormal Pap smear result used in this and previous studies in the Australian setting.

A unique contribution of this study is the in-depth exploration of the concept 'embarrassment', which is a commonly identified barrier described by women when asked about Pap smears. This study provides insight into this concept rarely described in the literature, particularly the concept of 'intimacy'. In addition, this is the first study in the Queensland context to seek women's views about a self collected test for cervical cancer prevention. This research also contributes to local knowledge about Queensland women's knowledge of HPV and its role in the development of cervical cancer and what they think about the HPV vaccine.

This study also provided unique insight into the knowledge, attitudes and beliefs of an older cohort of women, as recent studies conducted in Australia have largely focused on younger women (Giles and Garland, 2006; Shand, Burney and Fletcher, 2010; Agius et al., 2010b; McClelland and Liamputtong, 2006). Although the age range for both the computer-assisted telephone interview (CATI) survey and focus groups was 20–69 years, the mean age of women who participated in the CATI survey was 43 years and women who attended focus groups were on average, 55 years of age. The inclusion of older women in research about HPV is considered important, as they have been poorly represented in previous research and the impact of introducing HPV DNA testing is anticipated to impact on this group considerably, given they are more likely to be in long-term monogamous relationships and have had extensive experience with screening (McCaffery et al., 2003; Cooper, Polonec and Gelb, 2011). In addition, women in their forties are highly likely to have children in their early teens who are eligible for the HPV vaccine and therefore will be asked to provide consent for their children to be vaccinated.

Gaining insight into what older women know and believe about cervical cancer prevention strategies is also beneficial given the influential role they have in their communities and families as sources of advice as mothers, grandmothers, and aunties etc, given their life experiences. Women in their fifties are also an important group to include in research, as Pap Smear Register (PSR) data reveals cervical screening participation rates start to decrease from the age of 55 years in Queensland (QCSP, 2012). This study also reveals information about other age groups including the youngest and oldest cohorts and in the quantitative phase enabled comparisons

between age groups and revealed age as an independent predictor of HPV knowledge and awareness of the vaccine. Information about women across all age groups is beneficial in identifying gaps in knowledge or misconceptions that may influence these women's participation in cervical cancer prevention strategies, especially given the advances in technology that are impacting on the NCSP including vaccination and new tests. Women in this study were also more likely to have children and therefore their attitudes towards vaccination are highly relevant in the context of understanding the issues for women who are called on to consent for their children to be vaccinated. This study also provides insight into the knowledge, beliefs and attitudes of women who have extensive experience with cervical screening over many years. The majority of women had had at least one Pap smear and 27% of women in the CATI survey and 38% of women attending focus groups, reported they had had between 11 and 20 Pap smears. They also reported in both the CATI survey and the focus groups that most of them had regular Pap smears every two years, and therefore by their own admission, are very experienced participants of NCSP.

The other valuable contribution the women in this study make relates to the timing of the study. This study was conducted in the first two years of the National Human Papillomavirus Vaccination Program (NHPVP) and potentially the only Queensland study conducted during the implementation phase of the vaccine in the Australian setting. Finally, the findings of this study describe where Queensland women seek health information they trust and what they consider are effective strategies for communicating new information about cervical cancer prevention strategies in their communities. This advice will assist the Queensland Cervical Screening Program (QCSP) and potentially the NCSP, in the development of effective communication and health promotion strategies informed by women themselves. The limitations of this study are described in the next section.

9.3 LIMITATIONS

9.3.1 Study Design

Response bias

CATI survey

There are a number of limitations that have been identified with the use of computer-assisted telephone interviews. Random digital dialling was chosen to

ensure the sample frame included potential participants with unlisted or new numbers and therefore addressed one limitation associated with CATI surveys that arises from white pages sampling (Dal Grande, Taylor and Wilson, 2005). Another limitation of CATI surveys irrespective of the sampling frame used is that with increased mobile phone usage, surveys relying on landline telephones may be more likely to reach older and retired or unemployed persons who stay at home, and less likely to reach young and more socio-economically disadvantaged people who cannot afford a telephone (Choi, 2004; Smith et al., 2009).

The use of quotas for age and oversampling to enable meaningful comparisons by SES reduced the impact of potential sample bias as a result of these limitations. Households were also contacted in the first instance, between 17.00 and 20.00 on Monday – Friday evenings and between 10.00 and 17.00 on Saturday and Sundays to ensure coverage of times when women, with the exception of shift workers, were least likely to be at work.

Another limitation of the study was the response rate of 47% when non-qualifiers were excluded. One reason for this may have been women's reluctance to participate in the survey given the sensitivity of the topic, especially as a number of hoax Pap smear surveys have occurred in the Queensland context in the past, one of which led to the conviction of a male caller (Thompson, 2006).

The response rate was also impacted by the one week timeframe in which the survey was conducted, which was necessary to assess the impact of the media campaign before the next media burst. The CATI facility recommended for future surveys, a minimum of two weeks in field to allow for call-backs to be better utilized for the sample size required. An overview of the call analysis conducted by the CATI facility is provided in Appendix Q.

The CATI facility also incorporated the following to minimise non-response bias:

- call algorithms to enhance the probability of making contact with sample items using customised call cycles to deal with engaged and not-answered calls
- scheduling and keeping appointments for call backs were made with respondents

- questionnaire routing and skipping to minimise respondent workload and eliminate the need for asking unnecessary questions
- applying logic and range checks on question responses where appropriate
- ensuring that every question is asked and is answered by the respondent
- reduction of respondent comprehension errors, and interviewer error addressed through the use of clear interviewer instructions and piloting
- processing errors including illegible responses have been minimised through the use of verbatim entry of open-ended responses, and interviewing and coding of survey responses by experienced, trained I-view staff (I-View Pty Ltd, 2008).

The consistency between HPV and vaccine awareness amongst women who participated in computer-assisted telephone interviews and focus groups and that found in other Australian studies conducted at a similar period in time, suggests there was limited response bias impacting on the findings of the CATI survey, despite the methods used and limited response rate.

Another limitation of CATI surveys is response fatigue bias; however this was limited through the study design by ensuring the survey was less than 20 minutes as recommended in the literature (Choi, 2004). The mean time for survey completion was 17 minutes and 45 seconds (I-View Pty Ltd, 2008).

Focus Groups

The use of snowball sampling and a priori recruitment of focus group participants may be considered a limitation in a quantitative study; however is considered appropriate for qualitative research (Liamputtong and Ezzy, 2005). The large number of participants in some focus groups also had the potential for more vocal participants to dominate the discussion in focus groups; however the facilitation skills of the researcher ensured all women contributed as noted by a number of observers and described in Appendix O.

Measurement Issues

CATI Survey

The use of prompted versus unprompted questions is associated with a higher apparent knowledge of risk factors than simple recall (Waller, McCaffery and Wardle, 2004b). In this survey, both prompted and unprompted questions were used and responses to prompted questions, such as risk factors for cervical cancer, revealed they also help identify misconceptions. For example, most women incorrectly believed family history to be a risk factor, which has not been revealed in unprompted studies, and high levels of uncertainty were revealed through inclusion of a 'don't know' response category (Waller, McCaffery and Wardle, 2004a).

A limitation of using unprompted questions used in this study was revealed in the focus groups when the term 'abnormal cells' was explored further. Women frequently responded that the purpose of the Pap smear and the meaning of an abnormal result was about detecting abnormal cells; however many women in the focus groups believed these abnormal cells were cancer cells not precancerous changes. Without the use of mixed methods and exploration of this in the focus groups, the findings of this study based on CATI survey results alone would have indicated high knowledge and awareness of the purpose of the Pap smear and the meaning of an abnormal result, when this was not necessarily the case. The use of prompted questions may provide more detailed assessment of this in future CATI surveys to determine if the results of this survey are more widespread than this study.

The use of non-validated instruments to measure knowledge and attitudes in the CATI survey is an additional limitation as the validity of these measures is not assured. These instruments need to be appropriately validated to fully discount the potential for systematic bias in future studies where these tools are used.

Another potential limitation of this study is the use of dichotomous categorical outcome variables, which have been criticised for leading to a loss of information and may potentially lead to a serious loss of power to detect real relationships between variables (Royston, Altman and Sauerbrei, 2006). The outcomes of this study that were derived from multivariable modelling using binary logistic regression rather than linear regression of continuous outcome variables therefore should be considered in light of this limitation.

Focus Groups

The use of the HBM, may also be considered a limitation of this study. More recent health behaviour theories such as the Transtheoretical (stages of change) Model, the theories of reasoned action and planned behaviour and social cognitive theory could have been considered more relevant to this study as they also account for a person's intention to engage in a particular health behaviour (Carpenter, 2012; National Cancer Institute, 2005; Sheeran and Orbell, 2000). Intention has been identified as a key predictor of behavioural performance and the lack of assessing a person's intention has been described as a significant limitation of the HBM (Sheeran and Orbell, 2000). Waller et al (2012), has proposed a model which illustrates the relevance of the HBM to cancer screening research that includes intention to perform the behaviour and the applicability of the findings of this study to this model and how it has contributed to intent is outlined in Figure 9.1. Despite this, it is relevant to reinforce that this study did not aim to measure screening intention; rather it was a descriptive, exploratory study about women's knowledge, attitudes and beliefs about primary and secondary cervical cancer prevention strategies to inform future communication strategies following the Renewal of the NCSP. The HBM provided an ideal framework for this study as previously discussed and therefore did not limit the achievement of the aims of this study.

Recall bias

Women who participated in this study were more likely to report they were regular screeners than women in the general Queensland population. Multiple attempts were made in the design of this study to attract un/underscreened women through the use of the CATI survey and oversampling in remote areas and areas of higher SES disadvantage where screening participation is found to be lower. Focus groups were also held with women across a range of locations and SES areas to attract a wide range of women to the study.

This may have been associated with the reliance on self-reporting of cervical screening status and history of abnormalities. There is evidence that women tend to over-report their screening status when self reported status is compared with laboratory or medical records, although consistency has been found between self reported abnormalities and registry data in NSW (Bowman, Sanson-Fisher and Redman, 1997; Howard, Agarwal and Lytwyn, 2009; Canfell et al., 2006).

There is evidence of potential over-reporting of screening participation in this study, whereby women may have under-estimated the length of time that had lapsed since their last Pap smear and over-reported their participation in cervical screening. Eighty nine percent of women in the CATI survey (Section 5.1) and 80 % of women in the focus groups (Section 7.1), reported they had had a Pap smear in the previous three years, whereas PSR data indicates only 69% of the eligible population in Queensland had a Pap smear in the triennial period 2007–2009 (QCSP, 2012). Alternatively this may reflect sample bias in both the CATI survey and focus group samples whereby women who consented to participate in this study were more likely to be regular screeners than women in the general population.

The implications of this on the results of the study are firstly, that the findings of this study may not be truly generalisable to the Queensland population and may not be fully representative of women who are unscreened or underscreened. In particular, the difference observed by screening status for cervical cancer/screening knowledge and the lack of association with other factors should be viewed with caution. Despite this, the findings of this study reveal that amongst women who report they are regular screeners, low levels of knowledge about cervical cancer/screening and HPV are common. If the women in this study are indeed more likely to be regular screeners and both samples are biased and unrepresentative of un/underscreened women, it is assumed, given the associations found between knowledge and attitudes, these women will have even lower levels of knowledge and less positive attitudes towards Pap smears and the HPV vaccine.

In addition, women in this study provided in-depth insight into a number of barriers, such as embarrassment, which have not been as comprehensively explored in many previous studies. They also discussed barriers experienced by women when attending for Pap smears that are supported by other studies including those that focused specifically on un/underscreened women (Van Til, MacQuarrie and Herbert, 2003; Blomberg et al., 2008; Smith, French and Barry, 2003; Waller et al., 2009). This suggests potential sample bias or over-reporting of screening status by women in the focus groups did not impact on the perceived barriers women reported when having Pap smears, and reflects despite a high number of women reporting regular screening status, one in five women in the focus groups were not regular screeners. It is therefore suggested the screening status of women in this study should be

viewed in terms of the limitations described above, which is more likely to result in an overestimation of women's knowledge if the sample is indeed truly biased towards regularly screened women.

In addition, there was potential bias due to self reporting of previous abnormalities, as women were not asked to specify the abnormality, therefore findings related to abnormal Pap smear history should be considered with this in mind, as women may also be referring to benign or insignificant abnormalities including technically unsatisfactory smears, candida albicans (thrush) and atrophic smear results as discussed in Section 5.2.3.

Data Quality – Focus Groups

There were some issues with data quality due to background noise or recording issues as described in Appendix O; however as there were consistent themes identified across groups and an observer present at the majority of focus groups, the impact on data quality was anticipated to be minimal given the number of groups that were conducted.

Methodological Triangulation

In hindsight, the use of focus groups to further explore issues that were identified in the CATI survey, such as misconceptions regarding screening recommendations, may not have been the ideal design for this study. Had the focus groups been used in the formative phase of the study, a number of the limitations described above regarding the CATI survey design may have been addressed (Ulin, Robinson and Tolley, 2005). In addition, issues raised in the focus groups, for example the cost of screening, could have been investigated further by other factors such as SES, which would have provided valuable insight into this emerging barrier in the Queensland context. This is worth consideration in future mixed methods studies.

9.3.2 Representativeness

This study was conducted with Queensland women and is therefore not representative of women from other parts of Australia, although some findings of the CATI survey are similar to those found amongst Victorian women (Pitts et al., 2007). Women in both phases of the study were more likely to be born in Australia than women in the overall Queensland population and women from countries other than

the United Kingdom, New Zealand and Oceania are underrepresented. This is likely to have been due to the inclusion criteria for the CATI survey as women were required to be able to understand and speak English and 100 women were identified as not having sufficient language to complete the survey as specified in Appendix Q. Focus groups were also purposively held with mainstream groups of women. Therefore, the findings of this study are not representative of women born in overseas countries other than the United Kingdom, New Zealand and Oceania.

The age of women in this study may be considered a limitation in that women on average were older than women in the Queensland population but this can also be considered a benefit as discussed in Section 9.2, as there are limited studies with older women. Women were also more likely to be from regional and remote areas that the Queensland population and to be more educated than women in the Queensland population, to be married or in defacto relationships and to have had children. The findings of this study therefore need to be considered in light of these limitations.

It is prudent to note, this study was not designed for exploring differences by ethnicity or Indigenous status. Additional studies have been undertaken or are in the planning phase with women from culturally and linguistically diverse backgrounds, lesbian women and Aboriginal and Torres Strait Islander women, which have or will be conducted by culturally appropriate researchers to inform the activities of the QCSP in the future.

Despite these limitations, this study has valuable contributions to make to this area of research, especially in light of the in-depth information obtained from the focus groups, which complemented the findings of the CATI survey, as this is the first large mixed methods study of women from remote, regional and major cities of Queensland since the implementation of the HPV vaccine.

The recommendations emerging from this study are described in the final section of this chapter.

9.4 RECOMMENDATIONS

The landscape of the prevention of cervical cancer in Australia is swiftly changing with the introduction of primary prevention within the context of a long-standing secondary prevention program, the NCSP. The Renewal of the NCSP aims

to ensure that all Australian women have access to an evidence-based program that continues to improve health outcomes of Australian women (NCSP, 2012b). Evidence suggests this renewed NCSP will include HPV DNA testing within the cervical screening pathway, although its role is still to be determined. Before changes are made to the NCSP, it is imperative that the uncertainties and misconceptions that are evident amongst women in this study and the wider Australian community, as found in other studies, are addressed. Failure to increase community knowledge of the risks associated with cervical cancer and HPV may lead to decreased perception of risk or increase the barriers to screening, especially if women suffer distress from a positive HPV DNA test. This may in turn impact on screening participation rates in this country, which have decreased significantly in recent years in many Australian states and territories (AIHW, 2012).

This study highlights the need for the following:

- Increased community education to raise awareness and knowledge of HPV as the necessary cause of cervical cancer and the benefits of primary and secondary prevention strategies.
- Clear and concise screening policy statements that are easy to interpret and communicate to women, the community and health professionals following the Renewal of the NCSP.
- Consistent training of cervical screening providers in sensitive examination techniques and informed consent, and education about HPV, cervical cancer and the NCSP.
- Increased access to cervical screening through a reduction in costs associated with screening, the exploration of alternative service models and access to an appropriate provider.
- Further research into:
    - factors that impact upon women's participation or non-participation in cervical cancer prevention strategies
    - women's acceptability of HPV DNA testing and self collected testing for women who currently do not participate in the NCSP

- women's views about alternative screening policies including increasing the age of the commencement of cervical screening and screening interval
- culturally sensitive exploration of the above issues with women from minority populations
- further exploration of knowledge and awareness of cervical cancer, HPV and the HPV vaccine and attitudes towards vaccination amongst men and boys
- health providers' and relevant others' knowledge about cervical cancer/screening, HPV and attitudes towards the HPV vaccine.

- Utilisation of methods women recommend to inform communication plans for disseminating information about changes to the NCSP.

These recommendations are outlined in Table 9.1, and described in greater detail in the following sections.

9.4.1 Community Education

The findings of this study highlight high levels of uncertainty and significant knowledge gaps amongst women in Queensland about cervical cancer, the current cervical screening program, HPV and the HPV vaccine. In particular the link between sexual activity, HPV and cervical cancer needs to be explicit rather than suppressed as it has in the past (Cooper Robbins et al., 2010a; Juraskova et al., 2011; Braun and Gavey, 1999). There is a need to convey accurate information about cervical cancer and its association with HPV, in a sensitive way to avoid increasing stigma.

This is essential if women are to have accurate information upon which to base their decisions about screening, and for parents and their children to make informed decisions about HPV vaccination (Marlow, Waller and Wardle, 2007). This also aims to reduce the stigma associated with the diagnosis of a sexually transmitted infection for women who receive a positive HPV DNA test should this be introduced in the near future (Waller et al., 2005; Braun and Gavey, 1999; Juraskova et al., 2011).

Table 9.1 Recommendations: The Impact of Primary and Secondary Cervical Cancer Prevention Strategies Amongst Queensland Women

Key Finding	Strategy	Recommendations

High levels of uncertainty and knowledge gaps about cervical cancer/screening, HPV and the HPV vaccine	Increased community education	• Make explicit links between cervical cancer, HPV and sexual activity to:
		  • Enable women to adequately assess their susceptibility to and the severity of cervical cancer and HPV
		  • Promote benefits of screening and vaccination
		  • Reduce stigma and normalise HPV infection as a likely outcome of sexual activity rather than the result of deviant sexual behaviour
		  • Reduce anxiety associated with a positive HPV DNA test

Misconceptions about the current NCSP policy	Clear and concise policy statements	• Ensure policies are easy to interpret, communicate and implement to avoid confusion that currently exists, particularly in relation to the eligible population

Extensive physical and psychological barriers to screening	Consistent training of Pap smear providers	• Ensure providers are appropriately trained to:
		  • Provide adequate information to ensure informed consent by those participating in screening or vaccination
		  • Provide screening in a sensitive manner that aims to reduce discomfort and embarrassment for women
		  • Recommend tests that are proven to be effective within the Australian context including new technologies
		  • Avoid the use of examinations that are not evidence-based and potentially increase embarrassment e.g. PVE

	Increased access to cervical screening	• Reduction of costs for women for screening • Exploration of alternative service delivery models, e.g. non-medical Pap smear providers and the one-stop shop concept
Limitations and areas identified for further exploration	Further research	• Factors that impact on women's participation, especially unscreened/underscreened women • Women's acceptability of HPV DNA testing and self collected tests • Women's acceptability of changes to the age range and screening interval • Culturally sensitive exploration of these issues with women from minority populations • Exploration of these issues with men and boys • Review of health providers and other relevant key informants such as teachers and pharmacists knowledge of cervical screening, HPV and the HPV vaccine
Women's views about how to communicate changes following the Renewal of the NCSP	Informed communication planning	• Utilise multiple methods of communication to ensure adequate reach given this study found awareness and knowledge differed by age, country of birth, educational, marital status and a previous history of an abnormality • Consider women's information needs when developing communication plans about new technologies and changes to the NCSP • Seek women's advice about ways to effectively communicate messages about prevention strategies within their local communities

With changes proposed to the NCSP in the future that will require women and the wider community to have increased understanding about HPV, it is increasingly important to address these uncertainties. These findings indicate that making the link between cervical cancer, HPV and sexual activity explicit is unlikely to cause alarm and will enable increased knowledge about individuals' perceived risks and susceptibility to cervical cancer and address the uncertainty that prevails.

This is especially relevant in supporting the rationale behind girls receiving the vaccine pre sexual debut, as some parents do not perceive that their daughters are at risk of HPV based on their belief that they will not engage in premarital sex. However, they may be unaware of the risk posed by prospective partners who have had previous partners, which is especially relevant in cultures where it is socially and culturally acceptable for males to have premarital sexual relationships (Braun and Gavey, 1999). Parents should also be informed about the benefits of vaccinating girls when they are young given the increased immunogenic effects of the vaccine when they are teenagers (Wright, Bosch, et al., 2006). Given the low level of concern expressed by women in this study about the vaccine promoting sexual activity, it is timely to talk openly about the relationship between HPV, sexual activity and cervical cancer, rather than avoid this discussion within the Australian context.

Community education also needs to address women's uncertainties about smoking and misconceptions about perceived risks, such as family history and hygiene. It is especially important for HPV positive women to be aware of the synergistic role of smoking given evidence suggesting smoking can increase the probability that an HPV infection will become chronic and potentially malignant (Vaccarella et al., 2008).

Misconceptions associated with HPV and cervical cancer, such as family history as a risk factor or that HPV causes infertility, need to be addressed to ensure women have accurate information upon which to assess the threat of HPV and their susceptibility to cervical cancer.

Community education also needs to address uncertainty about the purpose of cervical screening and highlights the importance of being very clear in health promotion messages that prevention is the main purpose of the NCSP. The use of the term 'early detection' occurs frequently in cervical screening literature and health

promotion resources, for example, the primary NCSP cervical screening resource is titled 'Early Detection is Your Best Protection'; however women perceive early detection differently to the intent of these messages (Cancer Council Qld, 2012; NCSP, 2012a; Jirojwong and Manderson, 2001; Hancock et al., 1996). Further research is warranted about whether women who do not have Pap smears out of fear they are going to be told they have cancer and subsequent cancer treatment, will be more inclined to participate if they know the test is for identifying precancerous changes caused by HPV, rather than cancer.

Ensuring cervical cancer and HPV is discussed more openly is essential if knowledge is to be disseminated more effectively and uncertainty is to be reduced, especially amongst women who have not been vaccinated against HPV. The vaccinated cohort in Australia are at less risk for cervical cancer; however they are primarily young women under 30 years of age, therefore older women must not be forgotten, given their risk of developing cervical cancer remains unchanged and the NHPVP is unlikely to impact on cervical cancer incidence and mortality for at least another decade (Brotherton, 2008).

9.4.2 Clearly Articulated NCSP Screening Policy

This study highlights widespread misconceptions amongst women in the community about eligibility in the screening program and the current NCSP screening policy. Many women erroneously believed Pap smears should commence at sexual debut despite this never being part of the policy in Australia. This misconception also reflects the complexity and ambiguity of the current NCSP screening policy and how difficult it has been to communicate this policy effectively given most women do not relate commencement of screening with an age per se. The policy for commencement combines age and sexual activity as follows: *All women who have ever been sexually active should start having Pap smears between the ages of 18 and 20 years, or one or two years after first having sexual intercourse, whichever is later* (NCSP, 2012a). This complex message was poorly understood by women in this study and reflects the need for clear policies and messages for women and the community. In most other countries with organised cervical screening programs the policy recommendation is simple and there is only one age, for example, 25 years of age and the requirement for having commenced sexual activity (National Health Service, 2012; Tacken et al., 2007).

Women in this study were also uncertain about ceasing screening at age 70 years. Women over 60 years of age are the least likely to have Pap smears, therefore it is important to engage with older women and provide them with accurate information about the benefits of participating in the NCSP, especially as older women have been found to perceive themselves to be at lower risk of cervical cancer than other women (Orbell, 1996).

This study has highlighted considerable confusion about eligibility for cervical screening and the renewal of the NCSP provides a window of opportunity to ensure a clear policy statement is developed.

9.4.3 Health Professional Education

High uncertainty and lack of knowledge about cervical cancer and the NCSP, raises questions about whether women attending for Pap smears are provided with the appropriate information upon which to make informed consent about screening. Health providers have been found to provide inadequate information about cervical screening as they assume women know about it given their experience with screening (Chew-Graham et al., 2006). Women need to know the benefits, limitations and harms associated with screening to make informed choices (Barratt et al., 2005). They also should be informed about the meaning of potential abnormal results and appropriate information about HPV prior to testing, given a considerable proportion of women in this study believe the result means cancer and anxiety and distress have been linked with poor knowledge of what an abnormal Pap smear means (Posner et al., 2006; Wardle, Pernet and Stephens, 1995; McCaffery and Irwig, 2005). Providers also need to be appropriately prepared to be able to discuss a positive HPV DNA test result with women to ensure this occurs in a sensitive manner that allays anxiety and reduces the stigma associated with receiving this result (McCaffery and Irwig, 2005).

The barriers and attitudes towards Pap smears that women described in the focus groups highlight that most women dislike this test. It also indicates that many women (almost six out of every 10 women in Queensland) present regularly every two years, to have a test they find embarrassing, uncomfortable and invasive, which suggests they perceive the benefits of the test to outweigh these factors (CSSB, 2011).

Women's compliance with regular screening, despite their dislike of Pap smears, and the presence of multiple barriers and limited knowledge about Pap smears was a key finding in this study. It was consistently found that women wanted a skilled provider they could trust, and this was often irrespective of gender. This reinforced the importance of establishing a relationship with a provider (familiarity) beforehand and ensuring Pap smear providers are appropriately trained and sensitive to women's needs (Robertson et al., 2003; Moore et al., 2000; Blomberg et al., 2008).

In addition to addressing physical discomfort, Pap smear providers need to be sensitive to women's psychological needs during the procedure and be aware that there is often a fine line between women's perceptions of appropriate and inappropriate behaviour in the context of 'intimate' examinations (Moore et al., 2000). There were many things women discussed that made them uncomfortable that could easily be addressed if providers were appropriately trained in sensitive examinations. For example, observing women to identify if the procedure is causing them pain, providing them with a reasonably sized sheet to cover themselves with, locking the door before starting the procedure and using an appropriately sized speculum. It was surprising how often women complained about *'the cold metal speculum'* in this study, given the increased availability of high quality disposable plastic speculums or the ease at which a metal speculum can be warmed under a tap.

These interactional skills are included in most cervical screening training programs however there are substantial differences in the educational preparation of Pap smear providers (Robertson et al., 2003; NCSP, 1997). Non-medical Pap smear providers undertake competency based training to become Pap smear providers and must abide by national competency standards; however medical practitioners are not required to complete specific training in cervical screening and are not always educated in sensitive examination techniques when medical students (Robertson et al., 2003; NCSP, 1997). This discrepancy in training requirements and quality standards should be addressed to ensure women are provided with a client focused service that takes into account their physical comfort and psychological safety during the procedure (Robertson et al., 2003).

Embarrassment and discomfort were frequent barriers described in this study. However, what was unclear was whether embarrassment was only experienced by

women during the Pap smear procedure itself, i.e. the speculum examination, or associated with having to completely undress for a breast examination and/or the digital penetration associated with the pelvic examination (PVE). This was not explored as it was not appropriate within the context of focus groups. There is ample evidence that physical breast examination compared to mammography has no benefit in the detection of breast cancer in asymptomatic women and the role of the PVE in screening for ovarian cancer is also not supported; however these procedures are still often included as part of the Pap smear procedure in the Australian setting (Westhoff, Jones and Guiahi, 2011; Cancer Australia, 2012).

This raises two questions, does subjecting women to these additional procedures further increase their embarrassment and vulnerability given they need to remove most of their clothing if a breast check is also performed, and does the PVE cause more embarrassment than just a speculum examination, which is all that is required for the collection of a Pap smear? Providers should be educated about the lack of evidence associated with these adjunctive procedures that may potentially cause women harm given the intimacy and vulnerability issues raised in this study, and deter them from having the most effective screening test, the Pap smear or its alternative following the Renewal.

9.4.4 Increased Access

Cost

The cost to women to participate in the program and access issues, such as a 'one-stop shop' where women could access breast and cervical screening at the one service, should be explored further. The NCSP is the only population-based cancer screening program in which most participants pay to be screened. Women participating in the NCSP can access free services if they know about them, for example, the Mobile Women's Health Service, which operates in rural and remote regions or some Sexual Health Clinics, but the majority of women access the general practice setting, at which they are required to pay a consultation fee. Women spoke of how this was often charged as a long consultation unless they were bulk-billed, which was often only available for health care card holders.

In addition, many women in this study discussed how they were encouraged to pay for the 'extra test', liquid-based cytology, and at the time the study was

conducted, one major pathology laboratory in Queensland was charging women a pathology fee, unless they were advised by the woman's GP she was financially disadvantaged. The marketing of new technologies for cervical screening, as superior to cytology, to health providers in Australia has been based on international studies where cytology is neither as sensitive nor specific and is therefore misleading especially when these providers may fear legal liability if they do not offer a supposedly more reliable test (Medical Services Advisory Committee, 2009; Qiagen, 2012). This highlights the importance of ensuring health providers receive advice about new technologies from the screening program and not just pharmaceutical companies with vested interests, particularly given the costs for these technologies are currently borne by women in the Australian setting.

These costs when combined can be quite hefty, up to $200 up front, and although most can be claimed back through Medicare, provides some explanation as to why cervical screening participation rates in Australia differ significantly by SES and question how equitable the NCSP is. Cost as a barrier to screening therefore, needs to be addressed as part of the Renewal of the NCSP.

Appropriate provider

Access to a familiar provider was also identified in this study given the high turnover of doctors, particularly in rural areas. This supports the need for alternative Pap smear providers, such as nurses who either travel to the area to provide cervical screening, including the Mobile Women's Health Service in Queensland, or local general practice nurses, health centre nurses or Aboriginal and Torres Strait Islander health workers who are trained and competent in cervical screening.

Nurses have consistently demonstrated their competence in obtaining high quality specimens and been found to be highly acceptable to women (Christie, Gamble and Creedy, 2005; Victorian Cervical Cytology Registry, 2012; Robertson, 2006). This role needs to be supported nationally with the cost of the pathology initiated by these providers funded through Medicare Australia or an alternative source. This will enable equitable access for women irrespective of where they live and increase the availability of appropriate providers for women.

The 'one-stop shop' concept was also raised in a number of focus groups as an enabler to cervical screening, where women could have their breastscreen and Pap

smear at the one visit. This currently is available in a number of settings in Queensland where the Mobile Women's Health Service works in conjunction with BreastScreen Queensland but has not been formalised so that it is available in all areas (QCSP, 2005). This model was explored in Victoria where BreastScreen nurses trained as Pap smear providers, and was positively evaluated by women and very successful in engaging with underscreened women who had not had a Pap smear for more than four years (Grainger, 2011). The 'one-stop shop' concept may therefore be a key strategy for encouraging older women to have Pap smears given the decrease in participation that is observed in women over 60 years of age, and is worth further exploration (AIHW, 2011).

9.4.5 Further Research

Factors impacting upon women's participation

Women's compliance with regular screening, despite their dislike of Pap smears, and the presence of multiple barriers suggests the notion of personal moral obligation warrants further investigation in future studies to determine if differences between women's perceived moral obligation impacts upon their participation in cancer screening (Tacken et al., 2007; Orbell, 1996).

Questions raised about barriers, including intimacy issues and whether the breast examination and PVE cause higher level of embarrassment, also warrant further investigation. As identified in Section 9.3.2, this study potentially was non-representative of un/underscreened women, therefore further exploration of factors associated with non-attendance amongst Queensland women is also warranted.

Acceptability of HPV DNA testing

With the renewal of the NCSP, there is a real possibility HPV DNA testing may be introduced either as a primary screening test or as part of alternative screening pathways in a cytology based program. It is unclear in the Australian context whether women will be comfortable with a different test to one they have become accustomed to and consider to be relatively reliable, especially as the test will detect HPV. Women's acceptance of being tested for a sexually transmitted infection rather than precancerous cell changes needs to be explored further (Maissi et al., 2004; Waller et al., 2005; McCaffery et al., 2006).

The role of self collected HPV DNA within an organised program, such as the NCSP, should also be considered, particularly for women who do not currently participate. Self collection could be an option in the clinic setting, which is a common practice for the collection of chlamydia and gonorrhoea tests in sexual health clinics (Costa et al., 2009). Another role for HPV DNA self collection could be targeted interventions for women who are not screening or have not screened for many years, which has been trialled with varying success in Europe and is in the process of being introduced into the Netherlands cervical screening program (Szarewski et al., 2011; Sanner et al., 2009; Kenter, 2011). Cervical screening programs could implement an intervention to send these women, identified through electoral roll matching, a self collection kit, which they can perform at home and send to the laboratory. Further research into both the technology for self collection and women's acceptance of collecting their own sample in the specific scenarios described above and the efficacy of self collected HPV DNA tests to validate the role of this technology across diverse populations, is warranted.

Women's views about alternative screening policies

With the Renewal of the NCSP, the screening interval for cervical screening may be extended from two yearly to every three or five years if the policy is to be based on international guidelines (Meijer, 2011; IARC, 2005). When the NCSP was formally introduced in 1991, a change in recommendations from one to two yearly Pap smears caused concern amongst women and providers. Women may not be comfortable with this change unless they are presented with information to reassure them this is a safe recommendation. It also highlights the need to review the role of Pap smear registers, which are currently back-up systems that send reminder letters to women when they are overdue for screening. If the screening interval is extended, the Registers will play an important role in inviting women to screen regularly as not all providers have invitation systems in place.

The reliability of the Pap smear did not appear to concern women in the focus groups, although this may be of greater concern if the interval between Pap smears is extended, as the silent nature of cervical cancer was an issue for some women and prompted them to have regular tests. This change may be even more dramatic, if both the type of test and interval change, and women may fear it given their lack of understanding about HPV, especially if they perceive it to be a cost cutting exercise.

Women may also be deeply concerned about raising the age of the commencement of screening, fearing young women will be placed at risk and highlights the need to explore women's attitudes towards changes to screening eligibility, especially as many currently believe screening should commence at sexual debut and do not think screening should cease, irrespective of age.

Culturally sensitive exploration

As this study was conducted primarily with women born in Australia, research needs to be conducted in a culturally sensitive manner with women from minority populations including lesbian, bisexual, transgender and intersex women, women with disabilities, women from culturally and diverse backgrounds and Aboriginal and Torres Strait Islander women as they may have differing knowledge, attitudes and barriers to screening. They may also have different sensitivities about HPV as a sexually transmitted infection and recommendations for disseminating information in their communities.

Further exploration of knowledge, awareness and attitudes amongst men and boys

Research into men's and boys' knowledge and attitudes about cervical cancer, HPV and the HPV vaccine is also warranted to gain community insight into these issues, especially given the recent inclusion of boys in the NHPVP in Australia.

Health providers' and relevant others' knowledge, awareness and attitudes

Women in this study consider health providers including pharmacists to be trusted sources of health information. In another Australian study the support of teachers for HPV vaccination has also been raised as important when parents are making decisions about vaccination for their daughters (Cooper Robbins et al., 2010b). Information about HPV and changes to the NCSP following the renewal will need to be communicated effectively to these providers to ensure they are well placed to provide accurate information for women and the wider community. The knowledge level of these providers is unknown and needs to be assessed to ensure they have access to appropriate information to assist them as key informants.

Understanding the crucial role health of providers play in promoting women's participation in screening and as sources of health information, highlights the importance of including them in any future communication strategies about the Renewal of the NCSP.

9.4.6 Communication Planning

It is important to consider how messages about HPV have been disseminated and consider health literacy given poorer knowledge of cervical cancer/screening is also associated with limited awareness of HPV, especially for women who have not had previous abnormalities or been reached by current messages and campaigns. Lower knowledge about HPV in women over 60 years of age may be viewed as somewhat irrelevant compared to younger women who may be seen to be benefit more from both screening and vaccination. However, the role of HPV DNA testing for women exiting the NCSP is being explored in the Renewal of the NCSP (NCSP, 2012b). If HPV DNA testing is to be incorporated into a new screening policy in Australia, it will be important to bear in mind that the results of this study suggest older women and married/defacto women's knowledge about HPV is limited. Therefore clear communication about the role of the virus will need to occur if these women are to have faith in an alternative test to the Pap smear and not suffer psychological harm in the advent of a positive test, especially as many of these women are likely to be in long-term monogamous relationships.

Education was found to be an independent predictor of HPV vaccine awareness in this study, which suggests that the communication strategy used for promoting the HPV vaccine may have been more effective amongst women with higher education levels and subsequent health literacy (von Wagner et al., 2009). The majority of information relevant to HPV has focused on the vaccine in Australia and has occurred through print, such as newspaper articles, brochures and posters, with limited television advertising, although there was substantial media coverage of adverse events (Cooper Robbins, Pang and Leask, 2011). Limitations associated with mass media strategies about the vaccine have been linked to the short lead time between the licensure of the vaccine and the roll out of the program in April 2007 (Moore et al., 2010). This has important implications for the Renewal of the NCSP and supports the use of multiple methods of communication if information is to have adequate reach.

The findings described above in relation to the HPV vaccine, suggest information about the vaccine has not been widely disseminated throughout the community and as documented, the media whilst raising awareness of the HPV vaccine, has provided limited factual content about HPV (Cooper Robbins, Pang and

Leask, 2011). In addition, variations in attitudes towards HPV vaccination that were not evident for general vaccination, also suggest mass media strategies may not have been effective for certain groups, such as women born overseas or those in areas of moderate socio-economic disadvantage. The majority of mass media promoting the HPV vaccine was print based, which suggests multiple strategies for disseminating information are necessary to reach all groups within the population.

During discussions about the PSR, it became evident that the register needs to be promoted more actively as a number of women were unaware of it. This could be the result of them forgetting they received a welcome letter, especially if they were registered in the 1990s and had never been overdue for a Pap smear, and therefore, have never been sent an overdue reminder letter. If the PSR becomes a 'prompt' register following the Renewal of the NCSP, it will be important to bear this in mind and develop a communication strategy to ensure women understand its functions.

The education of young women in schools suggested by women in this study to help normalise cervical screening as an activity women engage in to keep healthy, was identified as a motivating factor for having had a Pap smear in a study of American college students (Burak and Meyer, 1997). This may be less relevant if the age of commencement for screening is increased to 25 years of age following the Renewal given the time lag between education in schools and the first screening test; however there will need to be some mechanism, including a communication strategy for young women so they commence cervical screening at the appropriate age and do not consider it unnecessary if they have been vaccinated (Brotherton, Fairley, et al., 2010).

Communication strategies that utilise a number of approaches are necessary to reach the broad age range of women eligible for cervical screening. Web-based information, although not a frequent source of HPV vaccination awareness at the time the study was conducted; should be considered given the increased usage of the Internet particularly by young women. Word-of-mouth and the role women's organisations play in disseminating information through networks and peer support also needs to be considered in future communication plans.

Women in focus group discussions suggested multiple strategies and methods and felt it was important to ensure women with diverse needs would have access to information relevant for their comprehension, as no one method was considered

appropriate for all women. These strategies should be utilised and evaluated to determine their effectiveness and reach. Women's advice about effective ways to communicate and promote information about cervical screening and any future changes to the NCSP should also be sought in other parts of Australia and utilised. Women know their communities and how information is disseminated effectively. The importance of communicating any future changes to the NCSP should also commence in a timely manner to ensure women are comfortable with any future changes before they happen.

The recommendations from this study about the impact of primary and secondary cervical cancer prevention strategies amongst Queensland women are outlined in Table 9.1 and represented in Figure 9.2. The recommendations from this study (green boxes in Figure 9.2) are relevant to each step of the cervical screening pathway (purple boxes in Figure 9.2) and as demonstrated relate to multiple steps in the pathway and also to the NHPVP (blue boxes in Figure 9.2). This is particularly relevant to an organised screening program such as the NCSP as each step is important to ensure a successful population based screening pathway (CSSU, 2007c). The findings of this study therefore, have the potential to contribute to every aspect of the NSCP screening pathway and make contributions to the NHPVP as demonstrated in Figure 9.2, if the recommendations described above are considered within the context of the Renewal of the NCSP. This will maximise the impact of future communication strategies and potentially, the impact of primary and secondary prevention strategies for cervical cancer among women in Queensland, and potentially other parts of Australia.

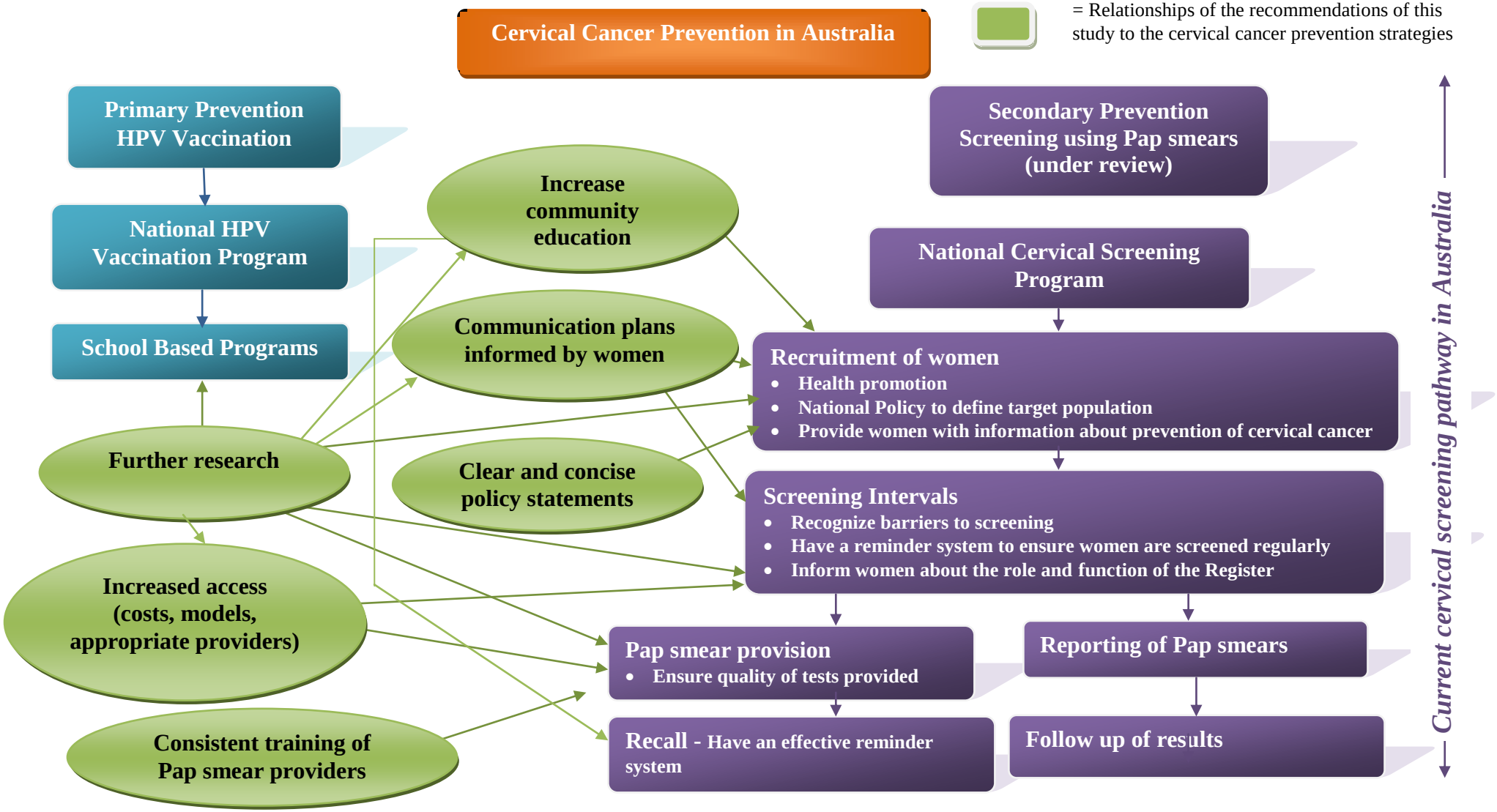

Figure 9.2: Recommendations of this Study in Relation to Cervical Cancer Prevention Strategies in Australia

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Appendices

Appendix A
Print Media Campaign and HPV Questionnaire

Final Draft June 2008

Hello, my name is … I'm calling from I-View on behalf of the Qld Health Department.
The Health Department is currently conducting interviews with women aged 20 to 69 years on aspects of health and health screening. May I please speak to the youngest woman living in the household who is aged 20 to 69 years.?
[INTERVIEWER NOTE: *For people who express concerns or wish to have more information*.]
If you would like more information about this survey or to check the validity of this survey you can telephone the Program Manager for the Queensland Cervical Screening Program within Queensland Health. You can contact her on 3234 1596.
Alternatively I can email, fax or post you a letter confirming that Queensland Health is currently conducting this survey. Would you like me to send this information, or would you like to continue the survey now?
[INTERVIEWER NOTE: *If the respondent wants further information, make an appointment to call back and pass the details on to your supervisor. Confirm fax number, email address or postal address depending on the method of contact requested*]
The interview is completely confidential and only takes about 15 to 20 minutes.
Can I just check, you said you are aged between 20 and 69 years?

1 Yes
2 No - *Terminate*
3 Refused to continue interview - *Terminate*

Good, thank-you. Before we begin, I should stress the importance of answering the questions as accurately as possible.
So please feel free to take as much time as you need before responding. If there are any questions you would rather not answer, just say so.
Some calls are monitored by my supervisor for training and quality purposes.
(INTERVIEWER: *If R is concerned about someone 'listening in' on their conversation, tell them that - "My supervisor sometimes listens to check that I am conducting the interview properly, and reading the questions correctly."*)

We may at any time during this interview be listened to by my supervisor for quality control procedures.
Today we are seeking information that will assist us to reduce the number of women who suffer from cervical cancer each year.
This means that we only need to interview women who have not had a hysterectomy.
A hysterectomy is an operation in which a woman's womb or uterus is removed. Have you had a hysterectomy?

1 Yes
2 No
3 Don't know
4 Refused to answer

IF 1 (YES) DISPLAY TEXT BELOW
As the survey is designed for women who have not had a hysterectomy I am not able to proceed with the interview but thank-you very much for offering to be involved. - *Terminate*
TERMINATION SCRIPT:
Once again, my name is _____ calling on behalf of the Queensland Health Department.
GOOD-BYE!

KN31 So that we can establish the boundaries of our interviewing area, can I ask what is the suburb, that you live in?

Insert SEIFA Code frame – assign to quintile and check quotas

KN 19a Could you please tell me your date of birth?
(INTERVIEWER: If respondent is hesitant about answering this question say: "We ask date of birth because most people find it easier to remember their date of birth than their age.").

1 Gave date of birth (type in date)
2 Refused to answer

IF (ANS = 1) SKIP TO Q1
IF (ANS = 2) SKIP TO KN19B

KN19b Well, could you please tell me: what was your age last birthday?

1 Gave exact age (type in age) ASSIGN TO AGE BAND FOR MONITORING
2 Refused to answer

IF (ANS = 1) SKIP TO Q1
IF (ANS = 2) SKIP TO KN19C

KN19c Would you be willing to say which of the following categories your age is in ?
(INTERVIEWER: Read out highlighted categories 1 to 6)
1 20 – 24
2 25 – 29
3 30 – 34
4 35 – 39
5 40 – 44
6 45 – 49
7 50 – 54
8 55 – 59
9 60 –64 or
10 65 – 69
11 No response

(Questions removed not relevant to this study)

The next few questions are about Pap smears.
KN1. Firstly, what do you think a Pap smear test is for?

(INTERVIEWER: Do not prompt. Multiple responses allowed. Probe fully)

1 A test to look for abnormal cells
2 Treatment for cancer
3 A test for a sexually transmitted infection
4 Other (specify)
5 Don't know
6 No response

KN2. A Pap smear is a test carried out by a doctor or health professional to check if a woman has early signs of cancer of the cervix.
How often do you think a woman should have a Pap smear?

(INTERVIEWER: If R having trouble answering, do not prompt with categories, just choose 'Don't know'.)

1 Every year
2 Every 2 years
3 Every 3–5 years
4 Every 10 years
5 Some other time period (specify)
6 Don't know
7 No response

KN3 When or at what age do you think it is recommended women should start having Pap smears?

(INTERVIEWER: Do not prompt)

1 16 years of age
2 18 years of age
3 21 years of age
4 When they become sexually active
5 Other (specify)
6 Don't know
7 No response

KN4 When do you think it is recommended women should stop having Pap smears?

(INTERVIEWER: Do not prompt)
1 70 years of age
2 At menopause
3 When they are no longer sexually active
4 No specific time recommended
5 Other (specify)
6 Don't know
7 No response

KN5 What do you think an abnormal Pap smear most commonly means?

(INTERVIEWER: Multiple responses allowed. Do not prompt with options. Probe with "Anything else")

1 Abnormal, precancerous cells
2 Cancer
3 Infection
4 Other (specify)
5 Don't know
6 No response

KN6a I am now going to read out a list of items. For each one please say if you think they might increase the risk of cervical cancer.
The first item is …….
Having many pregnancies/children
Do you think this might increase the risk of cervical cancer?

1 Yes
2 No
3 Don't know

KN6b The next item is: Being infected with human papillomavirus or HPV
Do you think this might increase the risk of cervical cancer?

1 Yes

2 No
3 Don’t know

KN6c–n Cycle through the list 6a–6n with the same question.
RANDOMISE STATEMENT ORDER.
6c Poor hygiene
6d Starting sex at a young age
6e Smoking
6f Having genital warts
6g Stress
6h Having lots of sex
6i Having lots of sexual partners
6j A family history of cervical cancer
6k Not having regular Pap smears
6l Taking the oral contraceptive pill
6m Not using condoms
6n Being overweight

Cervical screening behaviours

The next few questions are about you personally.

Q5 Have you ever had a Pap smear?
SINGLE RESPONSE
1 Yes
2 No
3 Not sure
4 Don't know about this test
5 Refused to answer

IF NOT CODE 1 (YES) IN Q5 SKIP TO Q8

KN7 How many times have you had a Pap smear?

(INTERVIEWER: Prompt with categories if necessary)

1 Once
2 Twice
3 3–5 times
4 6–10 times
5 11–20 times
6 More than 20 times
7 Don’t know / can’t remember
8 Refused to answer

Q6 When did you last have a Pap smear?
(INTERVIEWER: Prompt with categories if necessary)
SINGLE RESPONSE
1 Less than 1 year ago
2 1 year to less than 2 years ago
3 2 years to less than 3 years ago
4 3 years to less than 5 years ago
5 5 or more years ago
6 Don't know

Q7. What is the USUAL time between your Pap smears?
SINGLE RESPONSE
1 Less than a year
2 One year
3 18 months
4 Two years
5 Three years

6 Four years
7 Five years or more
8 Only ever had 1 test
9 Don't have a regular test
10 Other (specify)
11 Don't know
12 Refused to answer

KN9 Have you ever had an abnormal Pap smear result in the past?

1 Yes
2 No
3 Not sure
4 Refused to answer

(Questions removed not relevant to this study)

The following questions are about vaccines including childhood vaccines and vaccines for adults to prevent infections such as measles, mumps and rubella or influenza (the flu)
I am going to read you a list of statements. Please tell me to what extent you agree or disagree with each one.

RANDOMISE STATEMENT ORDER

KN12a
The first statement is: ***Prevention is better than cure for cervical cancer***

Do you…….:
(INTERVIEWER: Read out the highlighted categories 1 to 5)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN12b The next statement is: ***Vaccines are an important way to prevent disease***
Do you…….:
(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN12c (The next statement is): ***Everyone should be vaccinated against preventable diseases in childhood***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know

Refused to answer

KN12d (The next statement is): ***Vaccines that have been approved by the Health Department are safe***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN12e (The next statement is): ***All children should be vaccinated against preventable conditions while they are still babies***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN12f (The next statement is): ***The costs involved would influence my decision to have a child of mine vaccinated***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN12g (The next statement is): ***The convenience of the venue where the vaccine is given would influence my decision to have a child of mine vaccinated***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN12h (The last statement is): ***I worry about the side effects of vaccines for children***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree

Disagree
Strongly disagree
Don't know
Refused to answer

KN13 The following questions are about HPV or Human Papillomavirus.
Firstly, before today had you heard of HPV?

1 Yes
2 No
3 Don't know
4 Refused to answer

IF (ANSWER > 1) SKIP TO KN15
Next I am going to read you some statements about HPV and ask if you think they are true or false.
RANDOMISE STATEMENT ORDER

KN14a The first statement is:
A person may be infected with HPV and not know it
Do you think this is true or false?

1 True
2 False
3 Don't know

KN14b The next statement is: **Those with HPV may need Pap smears more often.**
True or false?

(INTERVIEWER: CYCLE THROUGH STATEMENTS IN THIS MANNER)

KN14c **HPV is spread through sexual intercourse**
KN14d **There is a vaccine to prevent some types of HPV**
KN14e **Women can often clear HPV without treatment**
KN14f **HPV can cause problems with pregnancy**
KN14g **HPV can be cured with antibiotics**
KN14h **HPV causes women to have abnormal periods**
KN14i **If you have HPV, smoking can increase your chance of cervical cancer**
KN14j **Condoms do not always help protect you against HPV**
KN14k **Certain types of HPV cause cancer of the cervix**
KN14l **The Pap smear is a test for HPV**

KN15 Have you heard of the vaccine for cervical cancer or HPV?

1 Yes
2 No
3 Don't know
4 Refused to answer

If (ANSWER > 1) SKIP TO KN18

KN16 Where did you hear about the vaccine?
(INTERVIEWER: DO NOT READ OUT. MULTIPLE RESPONSES ALLOWED – DO NOT PROMPT. PROBE WITH 'ANYWHERE ELSE?')
1 TV
2 Magazines / books
3 Newspaper
4 Radio
5 Doctor
6 Nurse
7 Health worker

8 Family / friends
9 Other (specify)
10 Don't know / can't remember
11 Refused to answer

KN17 Have you had the vaccine?

1 Yes
2 No
3 Don't know
4 Refused to answer

KN18 (INTERVIEWER: PLEASE READ OUT). A vaccine has been developed against two types of the virus, HPV or human papillomavirus that cause up to 70% of cervical cancer. This free Cervical Cancer vaccine is primarily targeted at girls aged 12 to 13 years of age who are attending school.

I'll now read you a list of statements that relate to this cervical cancer or HPV vaccine. Please tell me to what extent you agree or disagree with each one.

KN18c The first statement is: ***If I had a 12 year old daughter I would need more information before I could decide whether she should be vaccinated against HPV***
Do you…….:
(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN18d The next statement is: ***If I had a 12 year old daughter and my doctor thinks it is a good idea, I would have her vaccinated against HPV***
(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN18e (The next statement is): ***There is more risk involved in being vaccinated than in having HPV***
(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN18a (The next statement is): ***If I had a 12 year old daughter I would not want her to be vaccinated against HPV***

(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN18f (The next statement is): ***The cervical cancer vaccine works best when it is given before a young woman becomes sexually active***
(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

KN18b The last statement is: ***Vaccinating young women and girls against HPV would encourage them to become sexually active***
(INTERVIEWER: Read out the highlighted categories 1 to 5 if necessary)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know
Refused to answer

The next question is about tobacco smoking. This includes cigarettes, cigars and pipes.
Q23 Which of the following best describes your smoking status?
Would it be . . . . .
INTERVIEWER: READ OUT HIGHLIGHTED OPTIONS 1–5
SINGLE RESPONSE

1 I smoke daily
2 I smoke occasionally
3 I don't smoke now but I used to
4 I've tried it a few times but I never smoked regularly or
5 I've never smoked
6 Don't know / can't say – DO NOT READ OUT
7 Refused to answer – DO NOT READ OUT

Now we are coming to the last section of the study.
I am going to ask some routine questions about your background.
(INTERVIEWER: If R is hesitant about answering this sort of question say: 'These questions are important as they enable us to look at different groups within the community, for example younger people, those who are married, employed or retired and see whether those groups have different experiences. Remember all your answers remain confidential.')

Dem1 And what is your current marital status? Are you.....
INTERVIEWER: READ OUT CODES 1–6
1 Married
2 De facto

3 Separated
4 Divorced
5 Widowed, or
6 Never married
7 Don't know – DO NOT READ
8 Refused to answer – DO NOT READ

KN10 Do you have any children?
1 Yes
2 No
3 Refused to answer

IF ANSWER > 1 SKIPTO Dem3

KN11a How many children have you given birth to?

1 Enter number stated _____
2 Refused to answer

KN11b How many of these children are?

1 Males
2 Females
3 Refused to answer

(Questions removed not relevant to this study)

KN21 What is the highest level of primary or high school you have completed?
(INTERVIEWER: Prompt with categories if necessary)
1 Never attended school
2 Currently still at school
3 Year 8 or below (age 12 – 13 years)
4 Year 9 or equivalent (age 13 – 14 years)
5 Year 10 or equivalent (age 14 – 15 years) (Junior)
6 Year 11 or equivalent (age 15 – 16 years)
7 Year 12 or equivalent (age 16 – 17 years) (Senior)
8 Don't know
9 Refused to answer

IF (ANS = 2) SKIP TO DEM7

Dem 5 Since leaving school have you completed any further qualifications?
1 Yes
2 No
3 Don't know
4 Refused to answer
IF NOT 1 IN DEM5 SKIP TO DEM 7

Dem6 What is the highest qualification you have completed? Is it...
(INTERVIEWER: Read out categories 1–4
Use categories 5 & 6 only if R offers - don't probe for this information)
1 Bachelor Degree or higher
2 Trade Certificate (4 years duration)
3 Diploma or Certificate taking 12 months or more full time
4 Diploma or Certificate taking less than 12 months full time
5 Enrolled Nurse
6 Registered Nurse
7 Don't know
8 Refused to answer

KN26 Were you born in Australia?

1 Yes
2 No
3 Refused to answer
IF (ANS = 1) SKIP TO KN27
IF (ANS = 2) SKIP TO KN28
IF (ANS = 3) SKIPTO KN31

KN27 Are you of Aboriginal or Torres Strait Islander origin?

1 Yes
2 No
3 Refused to answer
ALL SKIPTO KN31

KN28 Which country were you born in?

1 UK & Ireland (includes England, Wales, Scotland and Northern Ireland)
2 New Zealand and Oceania (you will need to define Oceania)
3 Other (specify)
4 Don't know
5 Refused to answer

KN33 What is the postcode of your residence?

Well that's the end of the questionnaire. I just have one last thing to ask. Occasionally my supervisor will call some people back to check that I have conducted the interview properly.
Would you be willing to give me your first name only in case she wishes to call you?
1 Yes
2 No
That's the end of the interview.
THANK-YOU VERY MUCH FOR ALL YOUR HELP.
Once again, my name is _____ calling on behalf of the Queensland Health Department.
GOOD-BYE!

Appendix B
Focus Group Information Sheet

Queensland University of Technology
Brisbane Australia

PARTICIPATE IN RESEARCH

Information for Prospective Participants

The following research activity has been reviewed via QUT arrangements for the conduct of research involving human participation. If you choose to participate, you will be provided with more detailed participant information, including who you can contact if you have any concerns.

"Factors influencing the impact of primary and secondary prevention strategies for cervical cancer among Queensland women."

Research Team Contacts	
Leane Christie, Researcher Phone: 3328 9456 Email: Leane_Christie@health.qld.gov.au	Monika Janda, Phone: 3138 9674 Email: m.janda@qut.edu.au
Please contact the research team if you have any questions or require more information about the project	

What is the purpose of the research?
The purpose of this research is to find out what women in the community know about the risk factors for cervical cancer and what they know and think about the new cervical cancer vaccine as this will guide future health promotion activities in Queensland.
Who is funding this research?
The project is funded by Queensland Health. The funding body will not have access to personally identifying information about you that may be obtained during the project.
Are you looking for people like me?
The research team is looking for women aged between 20 and 70 years who have not had a hysterectomy.
What will you ask me to do?
Your participation will involve being part of a focus group with other women where cervical cancer, cervical screening and the cervical cancer vaccine will be discussed.
Are there any risks for me in taking part?
The research team does not believe there are any risks for you if you choose to participate in this research. It should be noted that if you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty.
Are there any benefits for me in taking part?
It is expected that this project will benefit you as each participant will be provided with information about cervical cancer and the vaccine to increase their understanding and knowledge about preventing this disease. It may benefit other women in Queensland as this study will be used to inform future programs and health promotion activities aimed at preventing cervical cancer.
Thank You!

Appendix C
Focus Group Consent Form

CONSENT FORM for QUT RESEARCH PROJECT

"Factors influencing the prevention strategies of cervical cancer among Queensland women."

Statement of consent

- By signing below, you are indicating that you:
- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or penalty
- understand that you can contact the Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project
- agree to participate in the project
- understand that the project will include audio recording

By signing below, you are indicating that the project has been discussed with you and you agree to participate in the project.

Name

Signature _____

Date / / 2009

Appendix D
Research Assistant Confidentiality Agreement

CERVICAL CANCER RESEARCH STUDY

I ....., agree to the following confidentiality requirements for the cervical cancer research study:

1. All information will remain confidential and will not be disclosed to another party without the approval of the researcher, Leane Christie
2. Confidential information includes:
    a. The names and contact details of participants
    b. Tape recordings of focus groups
    c. Written notes pertaining to focus groups
    d. Transcriptions and electronic files pertaining to focus groups
    e. The password of relevant computers
    f. All written information, tapes and data files pertaining to focus groups
3. All study materials will be kept in a secure place and returned to the researcher when transcription is completed.

Signed:.....

Date:...../...../20

Appendix E
Presentations Relevant to Study

Presentation Title	Event	Location	Date
Cervical cancer prevention: primary and secondary prevention strategies: does one size fit all?	Professional doctorate seminar QUT	Brisbane	March 2007
Promoting cervical screening following the implementation of the HPV vaccine in Queensland, Australia	2008 World Congress of Cervical Pathology and Colposcopy	New Zealand	October 2008
What Queensland women know about cervical cancer, cervical screening and HPV	21st Scientific Meeting of the Australian Society for Colposcopy and Cervical Pathology Inc	Darwin	August 2009
What Queensland women know about cervical cancer, cervical screening and HPV	National Cervical Screening Program Managers Meeting	Brisbane	December 2010
What Queensland women say about cervical cancer, Pap smears, HPV and vaccination	Queensland Cervical Screening Program Quality Management Committee Meeting	Brisbane	July 2011
What Queensland women say about cervical cancer, Pap smears, HPV and vaccination	CSSB 20 Year Symposium	Brisbane	August 2011
What Queensland women say about cervical cancer, Pap smears, HPV and vaccination	National Cervical Screening Program Managers Meeting	Melbourne	November 2011
What Queensland women say about cervical cancer, Pap smears, HPV and vaccination	Preventing Cervical Cancer 2011 Conference	Melbourne	November 2011
What Queensland women say about cervical cancer, Pap smears, HPV and vaccination	Cancer Screening Services Branch (CSSB) Consumer Reference Group	Brisbane	March 2012
What Queensland women say about cervical cancer, Pap smears, HPV and vaccination	Mobile Women's Health Service Annual Workshop	Brisbane	March 2012
Factors influencing the impact of primary and secondary prevention strategies for cervical cancer among women in Queensland	Final Seminar	Brisbane	May 2012
What Queensland Women say about Self Collected Testing for the Prevention of Cervical Cancer	Poster presentation – International Cancer Screening Network	Sydney	October 2012

Appendix F
Focus Groups Report

WHAT QUEENSLAND WOMEN SAY ABOUT CERVICAL CANCER, PAP SMEARS, HPV AND THE CERVICAL CANCER VACCINE

A report on the findings of focus groups conducted with Queensland women about cervical cancer, Pap smears, human papillomavirus (HPV) and cervical cancer vaccination

Leane Christie, Monika Janda, Kirsten McKenzie, Jennifer Muller

Report design by BIGGER BOAT CREATIVE SOLUTIONS biggerboat.com.au

ACKNOWLEDGEMENTS

This research was made possible through the support and assistance provided by the Queensland Country Women's Association, Zonta international, Queensland Women's Health Centres and work colleagues. This support enabled me to conduct focus groups with women across Queensland in metropolitan, regional and remote parts of the state. I am deeply grateful to these women who so generously shared their time and experiences with me to provide insights and understanding about women's knowledge and attitudes towards methods for prevention of cervical cancer including cervical screening and vaccination. Their generosity in giving their time, hosting a focus group and sharing their experiences with me provided rich and meaningful information to inform this study.

This research was also made possible through the support received from Cancer Screening Services Branch (Queensland Health) especially the Queensland Cervical Screening Program team and the School of Public Health, Queensland University of Technology, my supervisors, Dr Monika Janda, Dr Kirsten McKenzie and Ms Jennifer Muller, and family and friends.

PURPOSE

This report is for the women who participated in focus groups across Queensland to provide them with feedback on the findings of the study in keeping with the commitment I made to them when the focus groups were conducted.

AFFILIATIONS OF AUTHORS

Ms Leane Christie, Queensland Cervical Screening Program, Queensland Health and School of Public Health, Queensland University of Technology.
Dr Monika Janda, School of Public Health, Queensland University of Technology.
Dr Kirsten McKenzie, School of Public Health, Queensland University of Technology.
Ms Jennifer Muller, Cancer Screening Services Branch, Queensland Health.

WHAT QUEENSLAND WOMEN SAY ABOUT CERVICAL CANCER, PAP SMEARS, HPV AND THE CERVICAL CANCER VACCINE

A report on the findings of focus groups conducted with Queensland women about cervical cancer, Pap smears, human papillomavirus (HPV) and cervical cancer vaccination

Leane Christie, Monika Janda, Kirsten McKenzie, Jennifer Muller

Contents

Summary

Twenty three focus groups were held across Queensland between February and December 2009. The number of women participating in the focus groups ranged from five to 31. The average age of participants was 55 years. The majority of women were recruited through the Queensland Country Women's Association, were from inner regional areas, were married and had children.

Most women attending the focus groups had had at least one Pap smear and had had between 11 and 20 in their lifetime. Just over 60% of women attending the focus groups had heard of human papillomavirus (HPV) and 90% had heard of the vaccine prior to participating in the study.

The focus groups are part of a larger study looking at Queensland women's knowledge about cervical cancer and cervical screening, HPV and women's attitudes towards the HPV (cervical cancer) vaccine. The study started with a telephone survey of 1002 women in June 2008 and was followed by focus groups in 2009.

From the focus groups we found that:

As found in other studies conducted around this time in Australia, women's knowledge of the causes of cervical cancer and the associated risks of acquiring disease was limited and they commonly expressed uncertainty about these issues. Women acknowledged they had not thought much about it and related this to limited personal experience with or community awareness about cervical cancer, particularly when compared to breast cancer.

Most women had heard of HPV although many had limited knowledge about it and often they had heard of the name but little else. They had also heard of the vaccine and again their knowledge about it was often limited. Some women felt this was because they were outside the age range who were eligible to receive the free vaccine or they did not have daughters who were eligible for it.

Women overall had very positive attitudes towards cervical screening and vaccination and felt the Pap smear was important in protecting their health. Trust, particularly of their health provider was also an important factor that shaped their attitudes towards cervical screening and the vaccination. The Pap smear procedure itself however was largely viewed as uncomfortable, embarrassing and unpleasant and the option of a hypothetical new method, for example, a test that a woman could perform herself at home, was acceptable to many women although there were many reservations about self-testing that would need to be resolved for this to be widely accepted.

Ways to spread the word about cervical cancer prevention to women in the community include:

Women discussed how they get their health information from many sources including their general practitioner or local health service, pharmacies, libraries, mass media such as the radio, television programs and advertisements, magazines and the Internet. Women had many ideas on ways to promote and communicate new information and often these were novel ideas that they felt would work well in their communities. They considered it very important to use many different methods of communication and that any health promotion work to be done should take into consideration that women in the target population are from diverse age groups, religious and cultural backgrounds.

What methods are available in Australia to prevent cervical cancer?

Primary and secondary prevention programs are available in Australia as population-based strategies to reduce the number of new cases and deaths from cervical cancer. Primary prevention through the National Human Papillomavirus (HPV) Vaccination Program was introduced in 2007 whilst secondary prevention through the National Cervical Screening Program was formally introduced in 1991.

The National Cervical Screening Program aims to reduce illness and deaths from cervical cancer, in a cost-effective manner through an organised approach to cervical screening. The program encourages women in the target population to have regular Pap smears. The national policy as outlined below provides consensus guidelines on which women need screening and how often Pap smears should be provided. It states:

1. Routine screening with Pap smears should be carried out every two years for women who have no symptoms or history suggestive of cervical pathology.
2. All women who have ever been sexually active should start having Pap smears between the ages of 18 and 20 years, **or one or two years after first having sexual intercourse,** whichever is later.
3. Pap smears may cease at the age of 70 years for women **who have had two normal Pap smears within the last five** years. Women over 70 years who have never had a Pap smear, or who request a Pap smear, should be screened.

This policy applies to women with no symptoms and normal Pap smear results who should be screened every two years.

What were the focus groups about?

The primary aim of the focus groups was to determine what Queensland women say about cervical cancer, cervical screening, HPV and the HPV vaccine and what they think are the most effective methods of communication and health promotion should changes be made to the National Cervical Screening Program.

The study was conducted as there have been changes to the prevention of cervical cancer in Australia with the introduction of the HPV (cervical cancer) vaccine. It is also expected that there will be changes to the National Cervical Screening Program in Australia through the Renewal Project. It is therefore important to know what women currently know and say about cervical cancer, cervical screening, HPV and the vaccine so that any new information or changes to cervical cancer prevention policies take into account women's concerns, uncertainties or misconceptions **about these issues to ensure women's acceptance and confidence** in a renewed program.

The research questions to be answered by the focus groups were:

- What do Queensland women know about cervical cancer/ screening and what are their attitudes towards Pap smears?
- What do Queensland women know about human papillomavirus (HPV) and what are their attitudes towards the cervical cancer/ HPV vaccine?
- Where do Queensland women get their health information from and what do they perceive as the most effective methods of communication and health promotion should changes be made to the National Cervical Screening Program (NCSP)?

The Health Belief Model was used as the organising framework to guide the questions used in the focus group discussions which are outlined below:

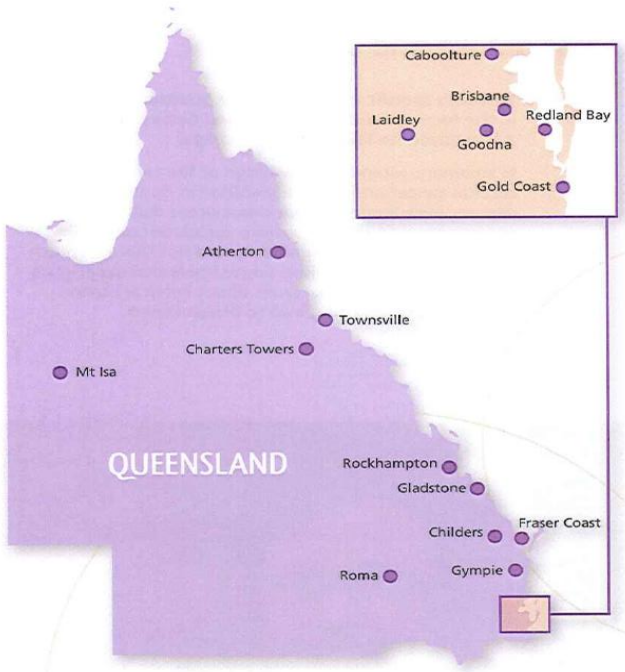
- What do you think of the following statement: "Good health is largely a matter of good luck"
- What do you think causes cancer of the cervix?
- Do you think every woman has the same risk of getting cancer of the cervix?
- If a woman gets cervical cancer, is there a cure? Do you think it would have a big impact on a woman's health?
- What do you know about Pap smears?
- What do you think prevents some women from having Pap smears or putting them off?
- If there was a test you could do yourself at home, do you think women who don't go for Pap smears now might do it?
- What do you know about human papillomavirus or HPV?
- What do you know about the new vaccine for preventing cancer of the cervix?
- What do you think would prompt a woman to agree for her daughter to have the vaccine or to have the vaccine herself?
- The QCSP has developed a number of ways to provide information about HPV and cervical cancer such as ads on TV, in magazines, brochures, posters and reminder letters. What do you think is a good way to do this?

How were the focus groups conducted?

Women were invited to participate in focus groups through community organisations and services, including the Queensland Country Women's Association (QCWA), Zonta International, Women's Health Centres and three social groups. The social groups were a church group, a Bookclub and a group of co-workers and friends from a metropolitan hairdressing salon.

Twenty three focus groups were held across Queensland between February and December 2009. The number of women participating in the focus groups ranged from five to 31 with the ideal range being eight to 12 women and 256 women overall participated in the study. Focus groups were held in the following locations [also pictured right], some of which are not named specifically to maintain women's confidentiality: Fraser Coast, Townsville, Gympie, Atherton, Goodna, Gladstone, Laidley, regional areas around Rockhampton, Childers (and surrounding areas), the Gold Coast, Morayfield, Caboolture, Mt Isa, a regional town near Roma, Roma, Charters Towers, two inner Brisbane suburbs and Redland Bay.

The majority of women were recruited through the Queensland Country Women's Association (41%), were from inner regional areas (45%), were married (63%) and 88% had children.



Most women attending the focus groups had had at least one Pap smear (95%) and most had had between 11 and 20 in their lifetime. Eighty percent of women said their last Pap smear was less than three years previously and 70% reported they had a Pap smear every two years. Just over 60% of women attending the focus groups had heard of HPV and 90% had heard of the vaccine prior to participating in the study.

The process for conducting the focus groups was standard in terms of the format but differed by the event. Some groups were conducted as part of Women's Health Events such as Pamper Days, in conjunction with regular meetings or events, or were held specifically for the purpose of the research project. The venues included QCWA halls, function rooms in hotels or clubs, women's health centres, local halls or function venues, a church and individual homes.

The focus groups were all conducted by me, Leane Christie, as part of my role as Program Director of the Queensland Cervical Screening Program and my studies towards a professional doctorate in public health. At the start of each focus group, I would introduce myself to women and asked them to read the information sheet and complete a consent form and a brief questionnaire if interested in participating. Once this was completed I would seek women's permission to tape the session and provide a brief overview of my background and the rationale for the study and the process to be followed for the focus groups. I also advised women that I would not provide any answers or correct them during the focus group but would provide an information session at the end whereby I would provide answers to the questions I asked and any queries that arose during the session. A topic guide was used to guide the flow of the discussion. The discussion was often informal, particularly in smaller groups akin to 'chatting over a cuppa' and aimed to provide a relaxed atmosphere for women to share their stories and experiences.

At the end of the focus group discussion I provided a brief education session based on women's responses to the questions asked during the focus group discussions. This session was therefore individualised to each group however similar topics were covered across all groups. This was especially important as women's responses were not challenged during the focus group discussions when incorrect responses were given so this ensured accurate information was provided at the end.

Women participating in focus group discussions were provided with refreshments when required (appropriate for the time of day in which the focus group discussions were held). At the end of the focus groups I provided women with a thank-you gift bag which included items such as some beauty products, flower seeds, a candle, a notebook and other miscellaneous items. This gift bag also included some booklets about Pap smears and HPV, a promotional pen "When did you last have a Pap smear" and a make-up mirror promoting the importance of regular Pap smears.

I asked women if they would like to be informed of the outcomes of the focus groups and those who were interested wrote their contact details on a register. This report has been provided for this purpose. An observer was present when possible at most focus groups to record observations about the group. These observers kept notes in a journal and were asked to document interesting things they noted about the process, the facilitator or the discussion. The audiotapes of focus groups were transcribed by the researcher and a research assistant and then common themes were identified and used to explain the findings. Ethical approval for the study was granted from the Queensland University of Technology University Human Research Ethics Committee (EC00171).

What did we find out?

Women's specific responses to the questions discussed in the focus groups are summarised below along with a few quotes to illustrate the findings.

In summary, women's knowledge of the causes of cervical cancer and the associated risks of acquiring disease were limited. There was a great deal of uncertainty and misconceptions associated with this and women acknowledged they had not thought much about it and related this to limited personal experience with or community awareness about cervical cancer, particularly when compared to breast cancer.

Women had heard of HPV although their knowledge was also limited and often they had heard of the name but little else. They had also heard of the vaccine and again had limited knowledge about this which they considered was due to their limited experience with vaccination given they were not eligible for it or did not have daughters.

Women's beliefs were strongly influenced by their experience, attitudes and knowledge about cervical cancer, screening and vaccination. In accordance with this, some women expressed concerns about the long term side effects of the vaccine, **expressed beliefs about the harms and benefits of Pap smears** and the vaccine and discussed factors within and outside their control that impacted on their health and their ability to participate in screening.

One of the most interesting parts of the discussion was the issue of barriers associated with Pap smears. These related to individual barriers such as discomfort, embarrassment, fear, denial and the fact that this is a test most women would prefer not to have. Within this discussion they were empathetic to women who did not participate and had many ideas about things to help women to participate more easily including a one-stop shop concept where women could have a Pap smear and breastscreen at the same visit. They also wondered why a less invasive procedure had not been made possible. When asked about a hypothetical test that a woman could perform herself at home by inserting a swab or tampon, women were very positive although some women were concerned about whether they would do it correctly or how reliable it would be compared to a Pap smear.

Despite their dislike of the actual Pap smear procedure, women overall had very positive attitudes towards cervical screening and vaccination and felt the Pap smear was important in protecting their health. Trust, particularly of their health provider was also an important factor to cope with the procedure.

Besides their health care provider, women relied on multiple other sources for health information and had many ideas on ways to communicate new information including novel ideas on how to do this. They considered it very important to use multiple methods of communication and take into consideration the diversity of women in the target population.

What do you think of the following statement: 'Good health is largely a matter of good luck'?

This question was asked to see if women in the groups considered they had some control over their own health and related to self-**efficacy. The majority of women did not consider health was** related to luck but that it was largely under the control of the **individual and could be influenced by good self management** including choices about diet, exercise, smoking etc and having regular health checks.

> I don't believe that good health is good luck. It's how you look after your body. What you put into your body - it's your lifestyle, you are what you eat.

Women generally considered they could control some factors of their health but other factors such as genetics, environmental factors and acute events were beyond their control and these latter factors were more often associated with luck.

> I think luck sometimes, if you have two people that lead the exactly same lifestyle and one, whether it's hereditary or not sometimes will develop something and another may not.

What do you think causes cancer of the cervix?

There was a lot of uncertainty expressed by women in response to this question and women also said it was something they had not thought about previously. There were also some women who believed it was information not provided to them, that is, they were not told about it.

> I don't know much about it really. We have Pap smears every year and hopefully that always comes back negative but as for anything else, I don't know.

Women who spoke of causes referred to infections including human papillomavirus (HPV), which at times was named but more often it was referred to as 'the virus' or sometimes 'wart virus'.

There were five focus groups where HPV was not mentioned as a cause although in many of the groups not all women had heard of it. In addition to HPV, other sexually transmitted infections were queried including bacterial infections. It was common for women to say this was all they knew and they had some uncertainty about where cervical cancer came from and whether HPV was the only cause. Women also thought there may be something that triggered the development of cancer cells or that made cells mutate.

I've heard that HPV, that can, that's human papillomavirus?

Yes but what if you already have the cancer cells in your body and you just need something to trigger it off?

Another emerging theme was the relationship with sex. Many women knew of a link with sexual activity. Commencing sex at a young age was raised and at times debated in some focus groups, the mechanics of sex, that sexual activity was a trigger or alternatively that having an active sex life was a protective factor were thought to be causes of cervical cancer.

As a kid I was always told, "Don't have sex or you'll get cancer of the cervix."

Could it have anything to do with say... sexual partners that are very aggressive?

Infection and behaviours that increased women's risk of acquiring an infection emerged often. Having multiple partners was frequently raised although in some groups there was debate about this especially when women reflected on women they knew who had developed cervical cancer. There was also some uncertainty about women who had never been sexually active and whether they were at risk.

I had a lady at work that I didn't disagree with it but she said that she'd been told cervical cancer came from having multiple partners and she's only had one partner and yet she's had cervical cancer.

I knew you got a lot of things from playing around with other people but I didn't know that's what you got from it.

Other factors that emerged in the discussion of this topic included factors women had some control over such as hygiene and personal cleanliness, stress, environmental factors and smoking. There was some debate about smoking as some women did not think it had any relationship with cervical cancer as it was mainly a risk for respiratory problems. Some women referred to keeping your immune system healthy and that a weakened immune system was an issue of relevance to HPV. Stress was also discussed in relation to the immune system.

Not cleaning yourself properly I suppose.

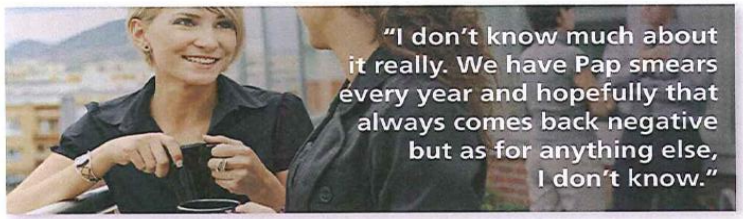
I believe your immune system (inaudible) ...inhibits the body's ability to deal with the virus.

The other group of causes related to other gynaecological conditions or issues such as endometriosis, polycystic ovarian syndrome, polyps, hormones and childbirth. Contraceptive methods were also queried as risk factors.

Medications? As soon as I went on the pill – I actually went on the pill at 17 as I had terrible acne and it helped reduce it and my doctor said you must start Pap smears within 12 months of going on that – even without the sex I had to have them because of the pill.

Genetic predisposition or family history was also discussed although at times women seemed unsure about this. On occasion they referred to breast cancer or cancer in general and the role of genetics and family history.

I think there is – my mother-in-law, who I didn't know, she died of cervical cancer. Her eldest daughter has sight of it, another one – she had it too. I think it might be hereditary.



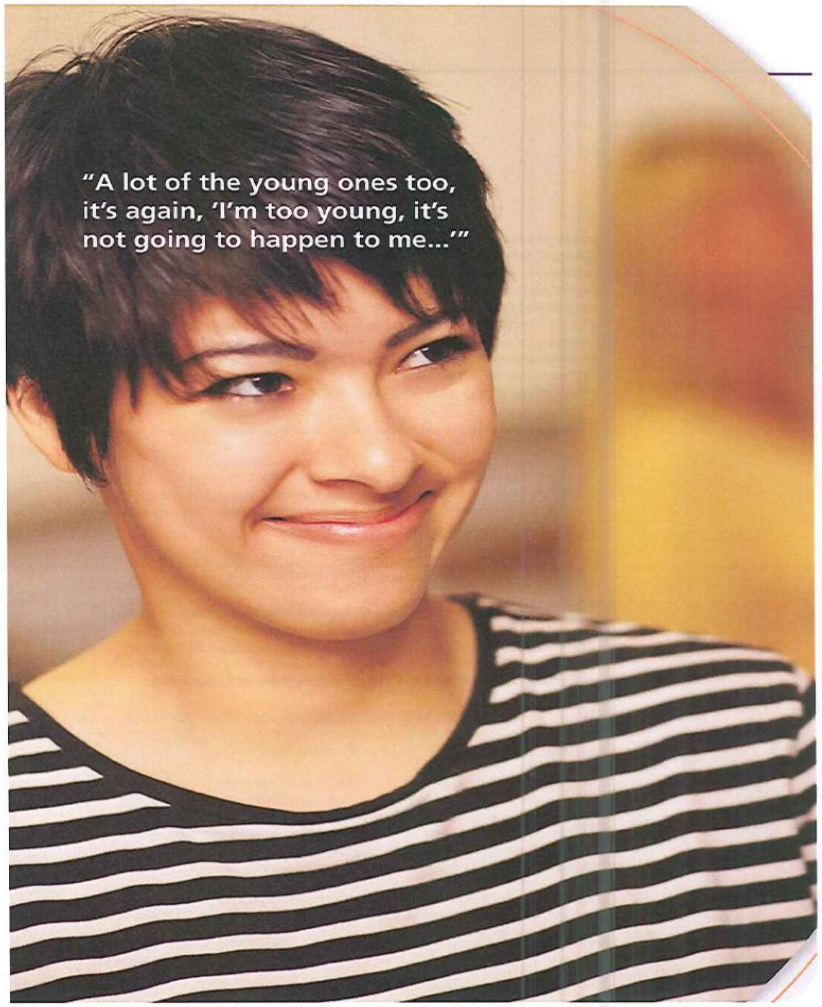
The emerging themes for perceived threat of cervical cancer were common across all groups with the exception of a small group of five older women who were all uncertain about what caused cervical cancer. There was much more discussion on this topic than the previous topic and at times the discussion led into the next topic about risk factors.

Do you think every woman has the same risk of getting cancer of the cervix?

There were some participants who felt women were all at the same risk and there were no factors that placed one woman at more risk than another.

> My view was that there was no prevention other than (inaudible) – (another participant - What?). The immunisation – Oh sorry yes, more recently there was the immunisation but beyond that I didn't have a sense of a lifestyle factor that could prevent it or anything... some people being more prone than the other.
>
> I'm not sure, it's just your number comes up and I'm not sure but I don't think there is a pre, um I have no thoughts as to why it's there or why some are more at risk.

The main risk factors women raised were associated with their knowledge of the causes of cervical cancer. This emerged particularly in relation to sexual activity and was linked with beliefs about women's behaviours or the choices they made in participating in risky or protective behaviours such as having regular Pap smears. When asked who was most likely to get



cervical cancer, there were many variations in responses. Many women felt it could affect women of any age although there were variations about certain age groups being at most risk. There were some assumptions made about young women's/girls' behaviours and beliefs which led to their thinking they were at a higher risk of cervical cancer whilst others were concerned for young women which was sometimes related to their beliefs about the commencement of screening and the target age for the vaccine. Other women were concerned that young women did not see themselves at risk so it was not on their agenda at all.

Yeah, I wouldn't think age would make much difference.

If it's linked to you know early sexual activity well certainly I think well maybe the age is becoming younger and younger – if it's linked to that – if that's one of the contributing factors. Because I think the young ones now certainly become more sexually aware and sexually active probably at an earlier age than the generation before.

A lot of the young ones too, it's again, 'I'm too young, it's not going to happen to me, it's going to happen to somebody else'.

There were similar themes to those identified as causes of cervical cancer such as sexual activity, infection with 'the virus' (HPV), and lifestyle factors such as smoking and genetics. In this topic however, different themes emerged during the discussion which reflected beliefs about individual risk factors or behaviours.

Somewhere in the back of my mind I still have the notion that it has something to do with the sexual activity, so I'm assuming the more partners you have, the more risk you're putting your body at.

I think it's also too, probably the type of, okay here we go, the type of partners you have. If you are from a lower socioeconomic bracket, I'm just thinking of [overseas country] where women ah, [ditto], 30% of the female population of [ditto] has HIV. They don't know about condoms, they don't know about preventative measures, simply because it's against their religion.

In general I think it is more acceptable for people to be sexually active and to have multiple partners, you know you only have to turn the television on to see that.

I hear in country areas that people are often more sexually active because as one person once said to me, "There is nothing better to do in the town."

There was increasing discussion and debate amongst women during this topic as women became more engaged in the process.

If a woman gets cervical cancer, is there a cure? Do you think it would have a big impact on a woman's health?

When asked whether cervical cancer would have serious consequences on women's health and well-being, all groups talked about how there was limited community awareness about cervical cancer. Women believed there was low community awareness about cervical cancer as it was not talked about very often and this led to women feeling somewhat uncertain or not highly aware of the disease or of women who had had cervical cancer. When women disclosed they had had some personal experience with the disease, through their own experiences or from friends or family, they talked about the impact of early detection versus a delayed diagnosis which was seen to have poorer or more serious outcomes for women. They believed this was because it affected a private part of the body and older women in particular talked about how such issues were not readily discussed when they were growing up although it was thought it was more acceptable to discuss such things these days. There were also concerns raised in relation to the link with sexual activity and how others may make assumptions about you if you disclosed having cervical cancer.

No, I'm totally naive because I've had no connections – know nobody...

Yeah, and like if you think you're, what's the right word, if you're somebody who has only got the one partner and suddenly you're being diagnosed with it, you start to wonder you know people start to perceive that I've been... that word... I can't even get that 'promiscuous' word out!

Well Australian people are more open - years ago people wouldn't have talked about things like that – people are more open today.

They also felt it did not have the prominence of other cancers, particularly breast cancer.

At this stage you can see, all the things about breast cancer – there's groups ... people making breast cancer quilts and motor cycle rides and walks and breast cancer – dragon boating, and I can't see women out there with t-shirts on you know - "I've had cervical cancer" you know? It's not the sort of thing that's going to be bandied about is it?

Well, breast cancer is everywhere isn't it.

During the discussions, some women expressed surprise at how little they knew about cervical cancer and some felt this was because it was not as common as other cancers such as breast cancer although this was a source of uncertainty.

The fact that I know virtually nothing about cervical cancer is quite an eye opener to me – now I realise it!

I think it is because people have been having Pap smears for as long as I can remember, and so the people that have regular Pap smears there is not so much cervical cancer or its detected earlier and treated when it's very minor and that's why it's been not so much talked about.

There were a number of women who knew friends or relatives with cervical cancer and a few women had been treated for cervical cancer themselves. I wondered at times if some women had confused cervical abnormalities with cervical cancer per se when recounting these experiences due to the treatment they said their friends or relatives had received. Women talked about abnormal Pap smear results and some were not certain what they meant, although some women understood that abnormal cells were not necessarily cancerous however this was rarely discussed.

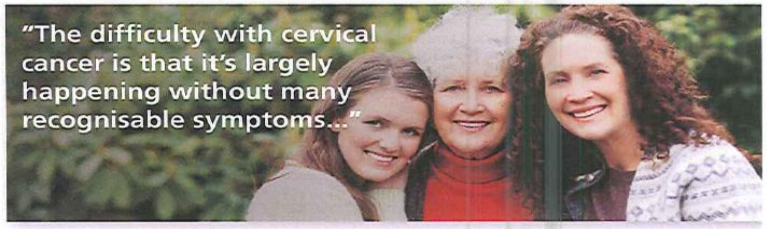
Um, well it was one after years and years of not having the test – and that's the secret – having the test..

My daughter had that, and she just went to one of those health centres and she didn't know that she had anything wrong and she just went and had this test done and found out she had these cells and she had to go down to the x Hospital in Brisbane and they did a laser treatment on her and she has to go back every six months I think for a check up but she hasn't had a lot of trouble.

And I don't even know if at those initial levels if it's called 'cancer' but people have an abnormal smear and ...

Women who knew something about cervical cancer described two outcomes relating to the impact of cervical cancer. The first was that cervical cancer was extremely serious and had led to the death of those who had been diagnosed with it. At one group women talked about a very recent death of one of their members from cervical cancer which prompted them to attend. Cervical cancer was described as a disease that had serious and negative consequences and was difficult to detect due to the lack of symptoms.

A girlfriend of mine had it many years ago – 30 years ago and she got cancer everywhere after that.



Yes, people don't have any signs at all and then by the time they do start to have symptoms, bleeding, pain, whatever ... of course, it is too late and it is already spreading or it's picked up its swag and then traced back.

The other outcome described was related to early detection. Most women firmly believed cervical cancer could be detected early and if it was it could be treated.

They discussed different treatment options that their friends or relatives had had, such as laser treatment, hysterectomy, radiotherapy and how these women lived many years after treatment. They also felt there were better treatment options available today. There was however some debate about whether treatment was available.

Well see, there is cancer and there is abnormal cells isn't there? So the abnormal cells that are pre-cancerous, they just do those cone biopsies where they just, you know, whatever they do, burn it out or whatever, and that removes the damaged cells and that's as far as they go. But if it's not abnormal cells, if it's later on - then it is cancer of the cervix.

My friend's had it and she said they got it early and she had surgery and she was fine and she didn't have any follow-up treatments or anything - she was quite lucky.

Oh yes, I've always been led to believe there's no cure for it.

On the whole women felt cervical cancer was a serious disease with negative consequences and that early detection (through screening) was important in reducing the impact of it. The notion of cervical screening as a method of preventing cervical cancer was rarely mentioned as many women believed Pap smears were used to detect cancer early rather that prevent it by detecting abnormal cells before they became cancerous.

It's a bit hard to check though, like even in Pap smears they don't always pick it up until late.

The difficulty with um cervical cancer is that it – and now I'm speaking from things that I've seen on TV, you know television advertising – it's largely happening without many recognisable symptoms so it's not

like you're gonna get a lot of symptoms in the early phases – so the things I've got from this advertising is keep up these regular Pap smears because you can catch it when it's asymptomatic and um, that it's quite a treatable illness in the early stages –you can have a hysterectomy if it hasn't gone through the rest of your system but if it's gone too far, that's when it becomes more difficult to treat.

There were similar issues discussed in all focus groups with lots of debate and discussion about treatment and early detection. In some focus groups this was a somewhat sad and reflective topic when women spoke about family and friends who had died from cervical cancer or recounted their own experiences.

What do you think prevents some women from having Pap smears or putting them off?

This question prompted much discussion and women often laughed and joked about some barriers and shared anecdotal tales about their experiences. It was not uncommon for the whole group to break into laughter at some women's experiences although at times there were also moments of anger or disbelief as others recounted their stories.

Women spoke of factors often identified in research about barriers to cervical screening with the most commonly identified perceived barriers to screening related to cost, time, discomfort - both physical and psychological, access issues, denial and fear. Women also talked about things that helped them to overcome some of these barriers including strategies they used such as not thinking about what was happening and what the provider could do such as warming the speculum, explaining the procedure or talking about something else. Women also talked about the benefits of reminder systems they received from their provider or the Pap Smear Register. In relation to time and cost women talked about other pressures on their time, difficulties accessing bulk billing for the consultation, being charged for pathology and having to pay for that 'extra test' which they often knew little about but agreed to it because the doctor told them it was more effective than the Pap smear.

Yes, sick children, sick partner - you're looking after them first... you put yourself last. Also the day your doctor works... having to take time off work to go and do it.

And even with making an appointment, they are hardly ever on time and that makes you want to put it off. And if you are working then this quick trip to the doctor can end up being half a day.

I've gotta work around when I can afford it. I've got a husband on full time medication... affording that medication – well I put off my smear for a few months until I can afford it.

Access issues included not having continuity of service especially in country areas where doctors changed frequently or their provider retired and also the availability of a female provider was important for some but not all women.

I had my last smear in June –(inaudible) - I had to wait 8 weeks from that date to fit in for a long appt to have a smear – I could have gone to whoever was the locum but if I wanted to go to my own doctor and I had to wait 8 weeks.

There is one this week and when you go back it's a different one. Then you have got to start all over again.

If you can get into a female GP, a lot of them aren't taking any new cases!

I had a female and she was rough.

I don't think gender, in that it comes up – it's in the skill of their hands.

Women also talked about cultural barriers although many of these comments were made by women not from the culture concerned.

Culturally – for some women from some cultures ... if it is male dominant, I think women find that very difficult where they're strange – like having a male or anyone do Pap smears. I think cultural differences.

Denial and fear were other reasons discussed where women talked mostly about others and that this was a barrier for underscreened women. Fear of the procedure and fear of the result and treatment were also raised in this discussion.

Or they are in denial, they don't really want to know, they think if I find out they have to do something about it, if they don't know about it, bury my head!

Isn't it a risk that some women simply don't see the need to have Pap smears?

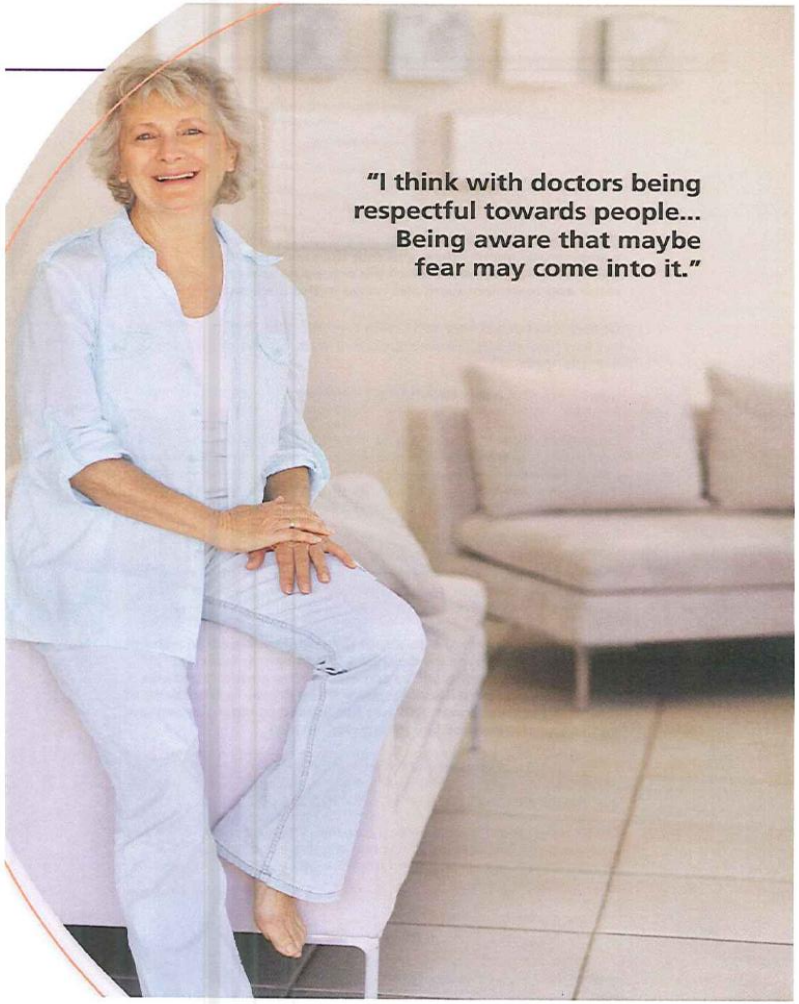
I think with doctors being respectful towards people – I think sometimes doctors want respect and (inaudible) and yes, it is another procedure and I think that's when this happened, he said with the procedure – let's get it over and done with – being aware that maybe fear may come into it I think is very important for doctors to be aware of.

It's because I think years back if you have cancer you died and just don't (talk about it) you know the 'C-word' they used to say you'd just die and I've got experience and people don't want to know they have got cancer, it's scary to them, many of them will hide away and the family will even distance themselves.

There was a lot of discussion about discomfort and embarrassment as barriers. Women mostly described Pap smears as invasive, horrible and degrading and as something they endured because of the perceived benefits which were often driven by the advice of their health professional. This was not limited to older women and was frequently discussed by young women also.

I think too a lot of empathy for women who have never been – I think we all say – it's invasive and it's yuk but we're still fronting up – whereas, perhaps people like x's mum who's never had one.

But it's just that it is something very personal and private – thank you! And you don't look forward to it sort of thing and you're not. But somehow it's personal but you think I've got to do it, every two years I've got to do it.



Discomfort was discussed as both physical and psychological discomfort as women often used the terms 'uncomfortable' in reference to pain or embarrassment. Physical discomfort was described as the provider being 'rough', the use of cold instruments and the position itself.

I don't feel particularly embarrassed but it's just uncomfortable. Yeah, the cold speculum and that sort of screwing thing.

That bloody cold silver thing! (laughs)

And it can be painful and some people can have a lot of trouble with it – yeah getting in the right position so it's not painful.

Psychological discomfort related to women feeling vulnerable, especially in relation to the position, the invasiveness of the procedure, embarrassment and also women's previous experiences that had been unpleasant.

That's it – it doesn't matter if it's a man or a woman I just don't feel comfortable with some strange person fiddling around.

Uncomfortable - that is the main thing because I don't think it has a whole lot to do with the pain because there is no pain, it's uncomfortable but it is more uncomfortable if you are in a very vulnerable position I guess.

I did go to another GP and I felt so embarrassed at how he treated me. He stripped me off, I had this little skimpy sheet and the way I was treated I would have never gone back.

Embarrassment was an area I explored in detail as this is frequently cited as a barrier by women but I was particularly interested in what they found embarrassing and I was surprised at how complex this was. Embarrassment included shame about the procedure itself including the position. Privacy and modesty issues were also discussed including concerns about others being present, invasiveness and vulnerability. Familiarity with the provider was also discussed as important for some women but for others this was a barrier.

Well I don't like having mine because you have to take your pants off and sit there with your legs open and I don't like doing it especially if it's a male.

It might be part of the job but still it's personal and I don't think you do ever get over that sort of thing and it seems to get worse as you get older.

But sometimes they used to have a nurse in the doctor's surgery if they had a male doctor - they don't now. I think that was more embarrassing – a young girl!

See I go to xx and she has been my doctor for a very long time and you become familiar, whether it's a male or a female it doesn't matter - you just gotta become familiar with your doctor and get to know them and honest to goodness there's no thought at all going on whilst this is happening.

Yes but when you go to your doctor, we've been going to our doctor for about 30 years but I don't go to him for a smear test because he's sort of my friend, you know, (laughter) I go somewhere else.

Women also talked about intimacy which was described in terms of having to expose what they considered a special part of themselves to someone other than their partner. On a couple of occasions this was discussed as a control issue by some men.

And even though doctors are covered by a code of ethics and things like that, it still is a very private part of your body that the only person really who has access to it is your husband and you know, it's sort of a bit of that...

If they're in a relationship - and they stop them going, you know.

Well I've only ever had one partner and he's the only other person who's ever touched ... and that's why, you know – someone else touching me in my private parts.

I actually think a lot of women sort of hold back because it's the actual thought – well it's not my husband looking down on there – it's someone strange so you're actually going to see and you're sort of thinking well it's not going to be private anymore.

The other aspect of embarrassment women discussed was their perceptions of providers' embarrassment. When discussing providers they also gave accounts of negative experiences and inappropriate behaviours that made them less likely to return to particular providers.

The thing is, it's embarrassing to us, but the doctor doesn't like having to do it either – like he doesn't want to have people's legs stuck up in the air – it's part of the job, so, it's embarrassing on both sides.

Although my doctor said 'it's just like looking at the engine of a car love, so don't worry'

I don't know about anybody else but I know whenever I go, and I have to go yearly now, even with my female doctor I still think jeez this poor woman and what she has to do... it's probably one of the worst things in her job, I feel really sorry for her and I know they have to do it but it is in the back of my mind that I really don't want to put my doctor through that.

Or as one doctor said to a friend of mine – that's disgusting!

The other thing we discussed was whether the embarrassment experienced during a Pap smear was the same or different to that experienced during pregnancy and this was a topic of much debate and discussion. For most women it seemed to be different and they often related this to labour pain and that the baby was their focus at the time. Age was also a factor they felt impacted on this issue.

Participant 1: Yeah but that's what I mean if you've had children, after you've had children you're not worried....
Participant 2: But I was the opposite – it didn't worry me until after I had my kids and then I thought, oh!?

And you feel comfortable doing everything you can whereas you've got no idea - to me you feel a lot more vulnerable going to get a Pap smear.

When you get in that labour ward you don't give a damn - you don't care – when I was having a breech they needed the students to come and have a look and you don't care – do what you like – just get the thing out! (laughs)

We discussed strategies to reduce embarrassment and enabling factors that made participating in the program easier. In these discussions there were differing opinions and women's attitudes were very individualised. Choice of providers and services including the role of nurses and the use of chaperones by male providers were also identified as enablers or alternatively as barriers by some. Service related issues included preferences for nurse Pap smear providers, the one-stop shop concept where women could have a Pap smear and a breastscreen at the one place, and access to free services irrespective of where women lived. The manner and attitudes of providers was also discussed and often in the context of reducing embarrassment and discomfort.

I just umm, I almost switch off – like as if I'm up here and what's down there is separate...

Disengage the head and think this is something you've got to do – get it over and done with as quickly as possible, get the instrument warm.

I think he's all right if I've got a cold but I'll go to a nurse if nothing's wrong – in that situation - I would be happy going there because that's all they did.

Well why can't they have Pap smearing clinics with the breast screening clinics so you can go get done –

If they've got the door locked – I've had some doctors not lock the door and the receptionist come in!

It doesn't do me any good that he tells me to relax.

Yes, the doctor just sort of talks and just quick conversations. And just things you can answer - he's taking your mind off what he's having to do and he knows you know you are not liking it too much and makes a general conversation, just, 'and how's such and such?' and it goes on...

Yeah if they go through what they are doing instead of shoving things inside and out.

Education and awareness raising were also identified as strategies to assist women to feel more comfortable with the procedure.

I think it might also be a lack of education, particularly amongst young women as to what it involves, what it's for, and even what age to start at because I still don't know what age you're supposed to start having a Pap smear, but I don't know what it involves, I don't know a lot about cervical cancer either to understand the push to have that testing regularly – and I think a lot of young people don't know about it.

Women also talked about reminder systems as enablers and some talked about how they did not like opportunistic screening as it did not give them time to prepare properly. Reminder systems such as the Pap Smear Register (PSR) and GP reminder systems were found to be beneficial although there were women who were unaware if they were registered with the PSR.

It's just not something that is on the forefront of your mind because you really don't know how long ago your last one was and when you get a reminder notice you think, oh okay it's time.

Participant 1: I know with me they don't send you a letter or anything to warn you, you turn up and the nurse says "by the way you're due" and you've got no time to think about it or mentally prepare or anything like that -
Participant 2: Or wear your good undies!

The Pap Smear Register is a real reassurance – you know people are chased up rather than trying to remember which year it was.

The other strategy women identified was that an alternative test should be made available given the current test was not that acceptable.

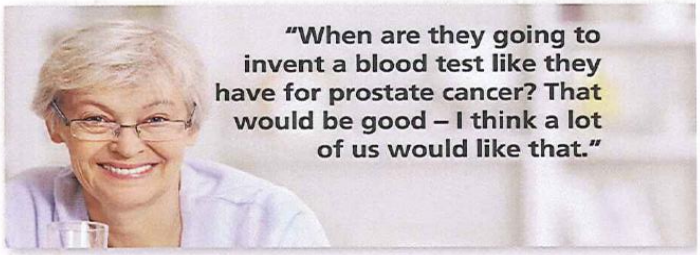
When are they going to invent a blood test like they have for prostate cancer? That would be good – I think a lot of us would like that.

I say let's have research and find some other way of doing it, why do we have to have it like that, it's time - because it's been going on for years like that, we need something new and different that will do the exact same thing.

A strategy I raised that was in the media at the time of the study related to self testing. I did not support a particular test as there was nothing available at the time that was approved as part of the screening program or publicly funded and discussed this as a hypothetical question. The question went as follows:

If there was a test you could do yourself at home, do you think women who don't go for Pap smears now might do it?

I was surprised at the number of women who supported this concept and how enthusiastic they were when it was first put to them.



I think that would be wonderful!

From my point of view I wouldn't have gone so long without it if I had something like that.

Yeah, a think of lot of women would do it – for sure!

I reckon you just wouldn't keep up the supplies to them.

However there were also strong opinions against this option. It became clear when I asked women what they would like to know about the test that they had a number of concerns and these increased the more they considered it. The main concerns related to how good it was when compared to the traditional test, whether they had the expertise to either do the test safely, accurately or hygienically and practical issues such as mailing and receiving results.

I just find it distasteful.

Oh no, I was just going to say I'm quite happy going and having a Pap smear, rather than doing it myself I think.

The mail is sometimes delayed – you know wet seasons and things like that – maybe sending a package – the test – you want to be reassured it is going to be delivered to the right place and that it's not going to be going around Australia somewhere.

If I knew it was going to be as equally as good as – the results as a professional, you know, I'd be happy with that but it's the fine line – is it as good as the professional and if you did it wrong you'd be mad at yourself – you know – why didn't I read the instructions properly or how come it went wrong - maybe I should have gone to a professional. Then I'd have doubts for the rest of my life and I'd be sick as well 'cause I had cancer. But anyway so maybe a professional – if you knew they were 100% but I've got my doubts they'd be 100%.

Women were also asked what they wanted to know about the test in order to have faith in it. This was included in the discussion to determine the information women would want to know should a new technology be available in the future.

That it's going to be accurate – there's no point doing something that comes back negative and then find out you have got something – that would be far worse.

I think the simpler – the thing – if you could do a thing – like a prick with a drop of blood and the instructions say I have to have a drop of blood 2cm in diameter and in this hole and I'll get a correct result and I can post it off – so if you felt that you weren't worried that you weren't going to do it right or if you had the proper sample or something like the smiley face then you would know that you're getting a proper sample so you could feel confident - Otherwise I'd just think I'll go to the doctor!

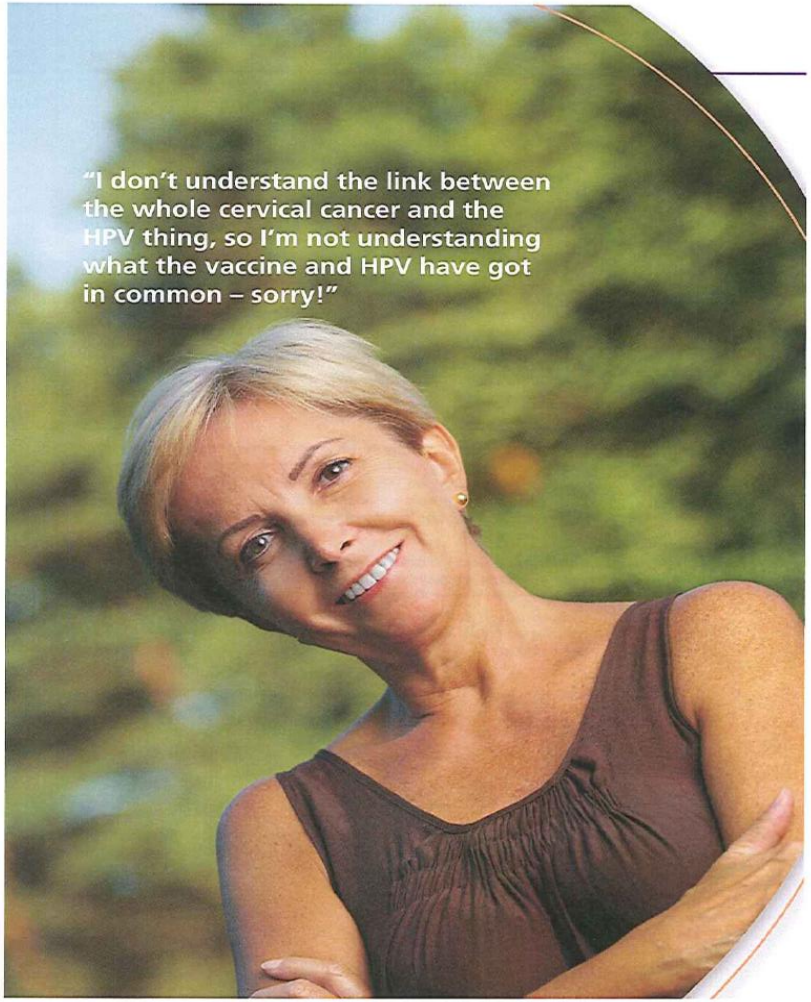
Despite differing views about self-testing, there was the view that underscreened women may participate if they had access to this test. Women also felt it was important to give women a choice so they could still attend a practitioner for screening if they preferred this option.

I reckon the best thing would be it to get different options to people so they can get the doctor to do it or decide to do it themselves and then maybe you'd get more people to do them.

I think it's probably a good idea – I think it can't hurt can it you know, for people who aren't going to doctors in the first place – and it's probably something that's –there's no negatives I suppose.

I think perhaps that market of people who are too embarrassed to go themselves or just don't want to do it (inaudible) - like the people that really want to know but still won't go to the doctors – you'll catch that segment of the market.

This topic created a lot of discussion and most women participated actively in this discussion as it was something most women felt comfortable commenting on. It was reassuring too that some women felt comfortable enough to disclose during the discussion they had not had a Pap smear for many years or spoke to me privately after the session. Women on the whole were empathetic to women who did not have regular Pap smears given their own feelings about this procedure.



Participant 1: Well I haven't had one for some years because I'm not sexually active and haven't been for years so...
Participant 2: I don't think that matters though.
Participant 1: Well no but I just don't like having them done.

I'm famous for not having all those tests – I won't go to BreastScreen and I won't do that either.

Especially if some women have been in a rape situation or violence they might be you know, scared or ashamed about going.

I had one of my daughters and she didn't want to have a Pap smear and had never had a Pap smear as she had been sexually abused and had this absolute fear of you know anything sexual basically and I'm sure there are other people out there.

This topic was the longest discussion area in each focus group. There were a lot of new information that emerged from this area of the discussion for me as a researcher particularly in relation to embarrassment and the concept of self testing. Women were highly engaged and motivated at this stage of the focus groups and the themes that emerged were consistent across all groups with the exception of access issues and cost barriers, particularly in areas of lower socio-economic status and more remote communities.

What do you know about human papillomavirus or HPV?

When asked this question there was a lot of uncertainty as a number of women had not ever heard of HPV or had heard of it but knew nothing more than the name. The discussion was often more about queries and requests for clarification. Of those who said they had heard of it there was a lot of uncertainty and questioning of each other about the natural history of infection, especially in relation to its impact and association with cervical cancer. The notion of a trigger was again raised in the context of this discussion as was uncertainty about whether the virus itself turned into cancer or caused its development.

Isn't papilloma a wart? – Ok that's what I know (lots of laughter) ... Only 'cause my little dog just had it and the vet called it papilloma!

I was going to say "what in the?" what is that?

Well the other cancer that was touched on was the ovarian cancer so can it lead to that, was my question more than anything else?

So the HPV could be something that is just sitting there and it's there, it's just a lump or whatever. See this is what I don't ... you know is it a lump or is it just a tissue change because to me a normal cancer is just a growth or, the way I, my perception of the cancer. But like the skin cancer is not a growth, it is a change.

Well it goes through stages; the virus goes through stages until it turns to cancer, I assume.

I don't understand the link between the whole cervical cancer and the HPV thing, so I'm not understanding what the vaccine and HPV have got in common – sorry!

I was wondering if it's been proven if someone has HPV, does that necessarily mean they are going to get cervical cancer, I mean is there much evidence for that? So they're two separate things then, HPV and cervical cancer. There's two separate and they're related?

There was also uncertainty about the impact of HPV on women's reproductive health such as infertility.

That's the virus that women are concerned about for when you have German measles when you are pregnant ... I think it's something to do with German measles?

I'm thinking that you could have that virus and never have a symptom. And it's just lurking in there waiting until – waiting until you are 35 are trying to have a baby and they say 'sorry you've had HPV since you were 15 and sorry'.

When discussing the impact of infection, there was some confusion about whether it was treatable although some women were aware the body could clear the virus. There was also some sense that it was an asymptomatic infection and that it was very common in the population.

Oh no, you can treat the warts but you can't treat the HPV.

That's what I was going to ask in relation to treatment, what about the vaccine?

No, I don't know actually but maybe not – not always because it can go away – stop.

I think it would be very, very common, I think a lot of people would have it. Like a lot of the population would have it and a lot of them wouldn't know they had it.

Common as in, I guess, it's more common that I thought – I didn't know anyone who had it until I had it and then all of a sudden I knew – all of a sudden a number of people said – 'oh, I've had that'.

It's an epidemic.

Women also talked about how it was transmitted and risk factors and there was some debate and questioning about its association with genital warts. It was also interesting that a number of women talked about sexual activity causing the activation of the virus (triggering it) and at times questioned if HPV was only a risk for women with a history of multiple partners. Women often did however talk about preventing HPV infection with the vaccine.

That was going to be my next question - this HPV - is it a sexually transmitted disease or is it something that can just happen or?

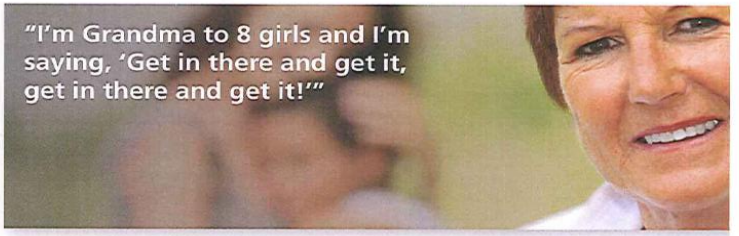
Well I thought after you were sexually active then you could get it, not necessarily via sex but I thought once you were sexually active, then the virus could develop in your body by having sex.

It's a virus. It is more likely if you've had multiple partners or your partner has had multiple partners.

...so if he had it first he'll transfer it to the other female... somebody said that all females have it and then the male activates it.

If someone gets the virus from a male partner doesn't mean to say they have multiple partners.

Isn't that what the girls are getting their injections for? So that is what it is stopping is it?



The age of participants was not necessarily reflective of women's knowledge about HPV as reflected in one observer's notes – 'Older women appeared more informed'. Uncertainty was widespread and the main emerging theme from around half of the focus groups was most did not know of HPV or had not heard anything about it other than the name or that there was a vaccine.

What do you know about the new vaccine for preventing cancer of the cervix?

There was awareness of the vaccine in all focus groups. At times, when it was first mentioned, women referred to Professor Ian Frazer and occasionally his colleague, Dr Zhou (who was not named specifically) and the role he played as a champion in raising awareness of the vaccine.

I think just like any cancers, early detection is vital and I think all of us have just praised Professor Frazer and his colleague, for the um, what he has done – 'cause hopefully our young women will not suffer like our friends have or our age group have, um, I think, you know, you hear a lot of people it is terminal.

Professor Frazer told us everything.

Like when he became Australian of the Year and something like that and they showed him in schools and things like that – stories in New Idea, Women's Day...

He's a Queenslander and he was Australian of the Year, like you know, he was in my life, you know, so you knew about it coming.

There was general acceptance of the vaccine although there were some women who had concerns about it which and at times related to the link with the virus, sexual activity and the target age of vaccination.

I'm Grandma to 8 girls and I'm saying, 'Get in there and get it, get in there and get it, get in there and get it!'

I think if people are linking HPV, cervical cancer to sexually transmitted diseases and you are giving it to a 12 year old then you are saying that your daughter, at that age is sexually active and most mothers will hope that their child isn't at that age, then it might give daughters the false sense that they can go off and do these things now.

There was a smear campaign going on about the immunisation – I remember one of our ladies, she brought a big spiel to one of the meetings and wanted everyone to read it and make sure they didn't get their children immunised.

Is that possible, is there one?

Women were more aware of the vaccine than HPV although there was still a lot of uncertainty about more detailed information and this was often framed in the context that they had not needed to know about it so had not sought or accessed further information. This included women who had consented for the vaccine themselves or on behalf of their daughters who at times acknowledged they had not properly read the information provided with the consent form.

They're giving it to young girls - that's all I know.

It doesn't protect against cancer – it protects them from getting the virus.

I've had it...but that's it. I've just heard it stops it.

Had I had a daughter I would know more about it but I only have a son.

Nope – they gave us a brochure but I don't think many people looked at it they were just like 'okay' then put it aside.

Women knew young women were eligible to receive the vaccine for free but had differing ideas of the age range that could access it and the association with sexual activity. At the time the focus groups were conducted there was a school based program for girls aged 12 to 18 years and a general practice catch up component for women aged 18 to 26 years. Therefore girls and women from 12 to 26 years of age could access the HPV vaccine for free.

From the time they are sexually active was my understanding. Oh well but no, it could be, at what age are they getting that thing?

Well I think they are saying um, they are not really recommending the vaccine for women in their forties say who have been married for a long time or saying that they are in a partner relationship for a long time where there is no likelihood of that person, I thought anyway...

How old did you say – 10? I must find out.

Is it two different strains? One for the schools when you are 14 and then one for –

Some women wanted to know why they were not eligible and at times raised concerns about equity. This was sometimes linked with confusion about the effect of the vaccine as some women thought it may be a treatment for HPV and worried they may miss out on the benefits of vaccination unless they paid to have it.

Yes but what does happen to the older women, is there something for us or, are we open to have that or is it only young women ...?

How come all the younger people can get it but the ones just over the actual like 24 and that can't get it?

Participant 1: It's a preventative.
Participant 2: No I don't think it's a cure it just prevents.
Participant 3: Yeah so if you've already got it, bad luck, if you have the vaccine you've got a ring of confidence.

Women also had differing views on the number of injections in the course of the vaccine stating between one and three injections and uncertainty about this was also evident amongst vaccinated women

and those who had consented for their daughters to have it.

Yeah – They had them at school – the first one was at school and the second one was at work so then they sent me to some clinic down here.

You just have one needle.

Concerns about the vaccine were raised and discussed within the context of information women had sought or wanted to know when asked **'What do you think would prompt a woman to agree for her daughter to have the vaccine or to have the vaccine herself?'** There were issues raised at times that there was limited information although some women acknowledged they had not taken a lot of notice of the information they were given.

Isn't it terrible? I didn't pay much attention, because I don't have daughters.

It comes with the information and consent and so on – I mean I would presume the child's been told about it at school. But I'm thinking – gosh maybe I should be telling them about it!

The most commonly cited information women felt they needed to know about the vaccine to consent themselves or on behalf of their daughters related to side effects. Women wanted to know about short term effects but also raised concerns about long term side effects that they believed may not have yet been identified given the vaccine was relatively new. Other information was mentioned but not as consistently as side effects.

Well I'm not concerned about all vaccines – I gave all my kids their vaccines – it's just that one. It's the unknown I think.

I was concerned about the side effects and the doctor sort of talked me through the fact that there wasn't much; there were a few side effects that came from it but they were minor like mild headaches or vomiting or feeling dizzy but I guess to me – I don't know much about different types of cancer but I know having cancer is not a fun thing so I sort of thought, well I'd rather take the precaution not to develop a form of cancer at least rather than develop it later on – that's what it ultimately came to for me to take.

You'd worry about the side effects I guess...if there's been enough research or time to know if there's side effects.

There's been some controversy around the side effects with it. The media jumped onto that one.

... like there's not much information about the positives and what the outcomes have been and they say you're supposed to get it – but where's the proof in that it has worked. That's probably one of my, you know you're debating whether or not to give it to your 12, 13 year old – how's it going to prove?

Discussion about the vaccine was not as lengthy or detailed as the previous discussion about Pap smears and highlighted **women's uncertainty about specific details related to the vaccine.** Knowledge about the vaccine differed across groups with some older groups knowing very little about the vaccine but this was not consistent and overall women were accepting of the vaccine, had limited knowledge about the eligibility criteria and were mostly concerned about side effects, especially in light of this being a new vaccine.

The QCSP has developed a number of ways to provide information about HPV and cervical cancer ... What do you think is a good way to do this?

The final topic discussed in the focus groups related to cues to action and sources of knowledge about screening.

The first question I asked in this section was **'Where do you get your health information from?'** as I thought it relevant to get an understanding of where women currently sourced information. Women described the sources they trusted which included their GP or health service and the pharmacy. They also talked about 'word-of-mouth' and their groups as they often had guest speakers talking about health topics.

Word of mouth, yes - Especially if you come up against something you've never come across - you ask people if they know anything about it.

But sometimes it's the blind leading the blind! You go to talk about something and what are you really achieving if you are asking the same question round and round and you are not getting any answer?

They had varying views of the Internet but considered health websites were a reliable source of health information and more commonly referred to media such as television, the radio and newspapers.

I suppose a few years ago I never looked at any health information but now I go on the Internet or MSN or if I know something's going to be on A Current Affair or Today Tonight or Four Corners or Australian Story, you know, I'm looking for it- what's on – but I think I personally get most of my information from the Internet.

Online and me, I Google everything – you get a symptom you Google it – I Google everything!

Umm, I just watched a program on it – Oprah (laughter) and she was doing the whole HPV and the doctor's program was doing it – um and yeah, just how you contract it and about the injection – things like that.

Few women considered magazines as a reliable source of information and the cost of these factored in to some women's decisions about them as an accessible source of advice. Women also recalled television advertising and posters they had seen about cervical screening and referred to the key message in the recent QCSP campaign but this was not always positively framed.

Participant 1: Women's magazines
Participant 2: I don't buy them
Participant 3: I just don't think they have enough information and too many ads and I can't afford them.

The ad on TV I'm sure it says you can get this HPV virus even if you've only had sex just once it said.

I don't like seeing that on television. It's just too personal and for the whole world to see. You don't want every man and his dog virtually seeing that sort of thing.

But those Pap smear ads when you sit down at night and you're having your cup of coffee – it's made me twice go and have my Pap smear.

I then asked how they thought we should disseminate new information for women about cervical screening by asking: **'There is a possibility that there will be major changes to the Pap smear program over the next few years so what do you think would be a good way for us to get new information out to women'?**

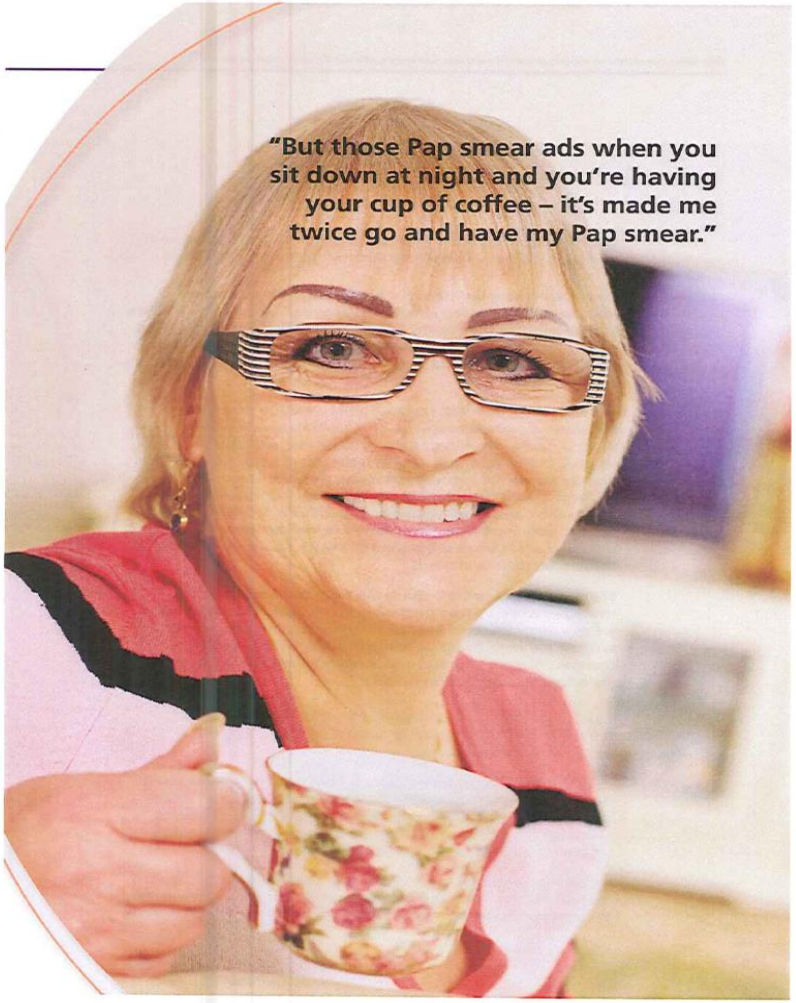
Women talked about the sources of information they had previously discussed as sources of reliable health advice such as mass media, networks, schools, health providers and the Internet but novel approaches and the use of personalised letters distributed via the Pap Smear Register was also raised. Women in all focus groups thought that multiple approaches were required due to the diversity of women by age, culture, location and other factors including literacy as women showed concern about specific groups or areas when suggesting strategies and were not just focused on their own needs.

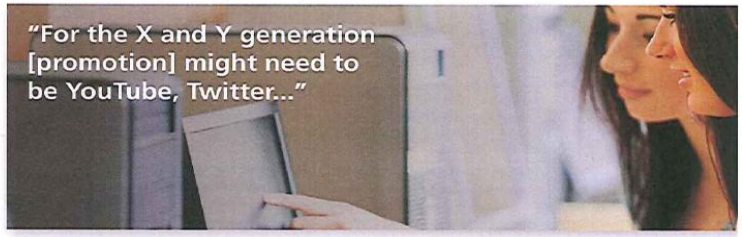
There was also a notable change in women's description of strategies whereby they used more active language about how we as a program could engage with women and get our message across if we were going to be successful at communicating such changes. Women felt mass media was relevant and it was deemed important to ensure optimal reach.

I don't think there's ever enough advertising of things like that. You know whether it's cervical or breast cancer or whatever, they don't always advertise enough.

If you know your community that really flows on from – there doesn't seem to be a blanket approach – we think in our community, our district, someone who knows that community would target that community – whatever it is – there has to be a resource person who knows that community and what works for the community.

No, because some people can't read, some people haven't got TV – you just need the media and have different formats and a cross-section of ages and cultures and having stuff in different languages.





In addition having a high profile media personality was thought to be effective although they did acknowledge it would be unlikely anyone would be that keen on going public that they had had cervical cancer.

But I do think it needs to be open more in the broader community. The way Sarah Henderson came across with breast cancer, everyone knew Sarah Henderson and most of us had a lot of respect for her. Maybe if they used someone like that to promote awareness of certain facts and maybe more people would take note if they did ... and maybe they need someone younger, I mean Sarah Henderson was sort of in our age group but maybe they need someone younger so the younger people are going to take notice and it will go with them through the rest of their life.

I think if, you know Max Walker does one of the bowel screening ads – so if you can get somebody who's well known –to be the promoter of it – if you can get someone that's a bit of a character to promote it.

Television programs in particular were considered effective and a common theme that emerged was they were a good way to promote health messages.

Well I found I often watch A Current Affair or those types of programs and if something takes my interest on that I will look into it further, I will use the Internet to find out more.

And we trust those shows when they have discussions like that on them (Insight and others) like, if you have interest enough like what we are doing now where you have the relevant people and your information that you take back from talking and the right people to talk about it.

Well a lot of people listen – well I don't watch those programs, you know Kerri-Anne said this or Oprah said that - I sort of think well what do they know? – but people do watch that - so some media personalities so people who watch that.

It also emerged that women's magazines would not be that effective however magazines that focused on health issues or specific groups including girls were suggested.

I was just thinking, there's a couple of good magazines that have good health things in them. Good Health. Is it Good Health? So that's another one that even younger ones might like because it appeals to young people's exercise regime.

I'd just like to know what happens to the oldies because for them it could be classified as a stigma and getting the message across to them you know... well I get the 50-something magazine as well and the seniors magazines and it would probably be nice to see some stuff coming out for the oldies as well.

Other strategies included convenience advertising such as messages on the back of toilet doors in shopping centres. Women also felt health providers and services were well placed to provide information. They also thought the Internet was relevant particularly a focused website, especially for young women.

I think the fact that we all have seen advertising is pretty good feedback – you know we've all seen the ad, we've all seen the back of the toilet doors, so...

Well doctors would know of course. Doctors themselves would have that information.

Indigenous Health Workers, our Indigenous Health Workers.

I mean the Internet will probably be for young people too. I don't spend a lot of time on the Internet but a lot of people do.

But for the X and Y generation it might need to be YouTube, Twitter...

Women also believed that women's groups and word-of-mouth were very important and effective ways to disseminate health

information. Putting information in school newsletters and education in schools was also raised as an important place to begin education and awareness raising and not just amongst girls.

...when we go back to our branches we should bring this topic up to discussing this topic because we feel as leaders in our community maybe we can be leaders to suggest that we can overcome some talking and maybe we could organise through our branches but that's just a side topic.

We need more education in private groups like this, where you feel more comfortable to talk about it.

Women talk, women get together and talk.

School newsletters and fitting it in the newsletters.

The child health nurse and the school nurse try to have all that covered. Depends on the school - if it's a state school they are more open.

There were also a number of novel approaches raised including mail drops, advertising in women's change rooms and having a specific week for cervical cancer like other cancers have. Women did caution on over-exposure though and referred to breast cancer as one subject that was somewhat over-exposed and also acknowledged the limitations of promoting cervical screening given the sensitivities involved.

They need that sort of sloganny thing – to give it a bit of a profile I think.

The Melbourne Cup luncheon here was breast cancer but I've never seen a Melbourne Cup lunch for cervical cancer...

Why don't you send something to people to catch the market you don't already have – (inaudible) – it might cost a bit to send it to all the houses - like just a postcard (inaudible) like one side of the thing says 'have you had a check' call this number – something little – short and sharp.

Participant 1: What does everyone do? We shop – so even if you had like Katies, your underwear stores or things like that – have it in an appropriate place.
Participant 2: The change room.

Participant 1: Same as a woman from a different culture – she might be afraid to talk to her mother or father or husband about it but she goes shopping – she's gotta buy clothes. So that pamphlet will be there for her in the change room.
Participant 2: Go a step further than that and get Sportgirl and places like that on side and have it on the tag, I mean when you buy something it– you know like if you buy this some of it goes to Breast Cancer or have like have you heard of this cancer or...
Participant 1: But I really like the change room idea – what a great idea! Because you can close the curtain / door and no-one knows you're reading it.
Participant 4: And that's why I like the toilet door.

Well you're not going to stick it on the side of a bus.

In the libraries when I get my books I bring free leaflets of what's on. If there's a free DVD there I'll take it home and watch it that night and my husband will too.

Women also felt it was important to begin communicating with them early rather than trying to convey a lot of information in a short time frame as this would not be very effective.

So if you're changing the program because you're gonna have to do a lot of lead up work rather than just saying we're changing in a few ads and that 's it – this is going to have to be a big education program around whatever changes there are.

I asked about sending a letter via the Pap Smear Register (PSR). This was readily accepted although women were a bit concerned that not all women were on the PSR especially those who did not have Pap smears and this was an important group to reach. It was also apparent women were unsure if they were registered on the PSR and that it was not as effective as the BreastScreen register. If a letter was sent via the register, women felt they would be more likely to open it if it were official looking with a logo and personally addressed to them. They wanted the content to be simple, clear and concise and felt something to catch their eye as a header would encourage them to read the contents.

You're only getting the converted.

I think you would nearly get everyone because you know when you go to the doctors it has to go to the laboratory and that's how you get that missed letter every two years – it's time – you're automatically on that list as soon as your test goes to pathology.

I don't think it matters what is on the envelope, as long as it arrives.

Not to the householder – it's junk mail – my husband would throw it.

If I got a letter saying something on the front like, you know, 'this is about your health, this could save your life' – you know, 'you are at risk' – you'd tend to – more people would just – select groups as such, would probably answer that because everyone interested in that.

I think like 'breakthrough!' or – 'Women's health issue!'

Women were very engaged through this discussion and had lots of ideas and methods to communicate new messages and cautioned against relying on one or two ways to reach women given the diversity of ages, cultures, geographical locations and literacy levels of the target audience.

There were similar themes identified across all groups although it was evident in a few groups that there were participants with marketing or health promotion expertise which was reflected in their responses.

Information session

At the end of the focus groups I provided a brief clarification/ education session based on women's responses to the questions asked during the focus group discussions. This session was therefore individualised to each group however similar topics were covered across all groups. This was especially important as women's responses were not challenged during the focus group discussions when incorrect responses were given to ensure accurate information was provided at the end. It was also a good opportunity to provide information for women who were very keen to know the answers to the questions I had asked and to respond to the questions women raised during the sessions. I also included brochures about cervical screening and HPV in the gift bags women received as a thank-you for attending the focus groups so they had written information on hand afterwards. These brochures are available at the following website:

www.health.qld.gov.au/cervicalscreening

Women's knowledge about cervical cancer and screening, HPV and the vaccine and their attitudes towards Pap smears and the cervical cancer (HPV) vaccine as found in these focus groups is similar to the findings of similar studies conducted in Australia around the time the study was conducted. This suggests there is the need for more effective methods of education and awareness raising about the prevention of cervical cancer in our community.

The contributions of women attending these focus groups have provided many insights and greater understandings about Queensland women's knowledge and perceptions of screening and vaccination against cervical cancer. The participation of women in these focus groups made this possible and I thank them for their time, for being so open and involved in the focus groups and for their interest in learning more about these issues during the information sessions. Without their involvement this study would not have been possible.

Recommendations arising from this study are included in the next section.

Recommendations from the study

- The findings from these focus groups show the need for more community education about cervical cancer, cervical screening, HPV and the HPV vaccine. As described, despite Pap smears being part of an organised screening program in Australia for more than 20 years, women have gaps in their knowledge about cervical cancer and cervical screening including the causes and risk factors associated with cervical cancer, when women should start and stop screening, what an abnormal Pap smear means and that Pap smears can prevent cervical cancer. Although many women had heard of HPV they had limited knowledge about it and its link with cervical cancer although there was awareness that a vaccine was available to prevent it.
- Messages about cervical cancer/screening, HPV and the cervical cancer vaccine need to be clear, concise and wide reaching. This is especially relevant for messages that promote Pap smears as a way to prevent cervical cancer rather than detect it and when Pap smears should start and stop as the current messages have not been effective.
- The Pap smear procedure and how to improve its acceptability to women need to be explored further. The majority of women dislike Pap smears and find them unpleasant, invasive and uncomfortable and feel vulnerable and embarrassed when having the procedure. These feelings need to be understood better by health professionals who provide Pap smears so they can avoid things that make women feel more uncomfortable during the procedure as described in the focus groups. Other methods for collecting tests for cervical screening should also be investigated further including self-collected methods, especially for women who do not currently have Pap smears due to embarrassment and discomfort.
- Some communities face barriers including access to an appropriate provider. Many women stated a preference for a female provider. However, other women thought there were more important provider characteristics than gender. These included the professionalism of the provider, that they were sensitive to their needs, were skilled and a reliable source of health information. They also preferred to have an established relationship with the provider but not be too familiar with them or socialise in the same circles.

- The cost of screening for women also needs to be reviewed given the cervical screening program is the only population-based screening program in Australia where participants pay to be screened. In addition, women should be given detailed information about the benefits of having additional tests such as liquid-based cytology and HPV tests as this increases the cost of being screened. Liquid-based cytology, which is often referred to as Thin-prep® as this has been the only product available in Australia until recently, has not been found to be more effective than the Pap smear in detecting high grade abnormalities. These tests are not part of the National Cervical Screening Program and the Pap smear is currently the best protection against cervical cancer although this may change in the future.
- Women's advice about effective ways to communicate and promote information about cervical screening and any future changes to the program should also be sought in other parts of Australia and utilised. Women know their communities and how information is disseminated effectively. The importance of communicating any future changes to the Program should also commence in a timely manner to ensure women are comfortable with any future changes before they happen.
- There should be more research into the methods of communication used by health professionals including general practitioners, nurses, health workers and pharmacists to convey knowledge about cervical cancer, cervical screening, HPV and the HPV vaccine. Women commonly seek health information from these providers however it is unclear how well informed providers are given the recent advances and new information about cervical cancer or whether they have effective resources to support them in the provision of health advice.
- Research should also be conducted in a culturally sensitive manner with women from minority populations including lesbian, bisexual, transgender and intersex women, women with disabilities, women from culturally and diverse backgrounds and Aboriginal and Torres Strait Islander women as they may have different levels of knowledge and attitudes, barriers to screening and recommendations for disseminating information in their communities.

What will happen next?

The information from the focus groups will be used in conjunction with the findings from the telephone survey to describe Queensland women's knowledge about cervical cancer, cervical screening and HPV and their attitudes towards the cervical cancer (HPV) vaccine. This will be presented in a professional doctorate thesis and the findings will be presented at local, national and international conferences. In addition, a number of research papers will be published to disseminate these findings more broadly and add to the knowledge currently published about this topic.

It is hoped the findings of this study will be considered by policy makers, health providers and health promotion officers when new screening pathways and tests and methods of communicating information about cervical screening are considered.

This report will be provided to all the women in the focus groups who requested it and is also available upon request for women who participated in the focus groups and did not provide their details on the day.

Feedback on the findings in this report is welcome from the women who were involved and the researcher would welcome the opportunity to present the findings or provide information sessions about cervical screening and cervical cancer prevention at relevant forums held by the organisations involved.

Additional information

Additional information is available on the following topics at the websites described below:

National Cervical Screening Program
http://www.cancerscreening.gov.au/internet/screening

National Cervical Screening Program Renewal Project
http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/ncsp-renewal

HPV and cervical screening information
http://www.health.qld.gov.au/cervicalscreening

Cervical cancer (HPV) vaccine information
http://www.immunise.health.gov.au/internet/immunise

Feedback on this report or further information about the study can be obtained by contacting Leane Christie on 07 3328 9466.

Appendix G
Variables Collected to Inform Phase 1

Variables	Dependent* /Independent	Research Question	How Measured	Type in survey
Knowledge of cervical cancer /screening	Dependent Independent	Q1&2 Q2&4	Individual items (choose answer)	Categorical
Knowledge of HPV	Dependent	Q1&2	Individual items (true/false)	Categorical
Awareness of HPV	Dependent Independent	Q1 Q2&4	Yes/no/don't know/refused	Categorical
Awareness of HPV vaccination	Dependent Independent	Q3 Q4	Yes/no/don't know/refused	Categorical
Attitudes towards vaccination in general	Independent	Q4	Individual items (Likert-type response)	Categorical
Attitudes towards HPV vaccination	Dependent	Q4	Individual items (Likert-type response)	Categorical
Age	Independent	Q2 &4	Age at last birthday (years)	Continuous
Location	Independent	Q2 &4	Postcode of residence	Categorical
SES	Independent	Q2 &4	Postcode of residence mapped to SEIFA index	Categorical
Australian born	Independent	Q2 &4	Yes/no/don't know/refused	Categorical
Indigenous status	Descriptive		Yes/no/don't know/refused	Categorical
Educational attainment	Independent	Q2 &4	Highest level of schooling & post school qualifications	Categorical
Marital status	Independent	Q2 &4	Married, single, divorced etc	Categorical
Parity	Independent	Q2 &4	Yes/no/don't know	Categorical
Smoking status	Independent	Q2 &4	Smoker (current/previous/never)	Categorical
Screening status	Independent	Q 2 &4	Length of time since last Pap & usual time between Paps- combo	Categorical
History of previous abnormalities	Independent	Q2 &4	Yes/no/don't know/refused	Categorical
Where heard of HPV vaccine	Descriptive	Q4	Nominated source	Categorical
Had the HPV vaccine	Descriptive	Q4	Yes/no/don't know/refused	Categorical

Appendix H
Knowledge and Attitude Measures

Cervical Cancer/Screening Knowledge Tool

Knowledge Item	Score (1 = correct answer)
What is a Pap smear?	
A test to look for abnormal cells	1
Treatment for cancer	0
A test for a sexually transmitted infection	0
Don't know	0
How often should a woman have a Pap smear?	
Every year	0
Every 2 years	1
Every 3–5 years	0
Every 10 years	0
Don't know	0
When do you think it is recommended women should start having Pap smears?	
16 years of age	0
18 –20 years of age	1
21 years of age	0
When they become sexually active	0
When do you think it is recommended women should stop having Pap smears?	
70 years of age	1
At menopause	0
When they are no longer active	0
No time recommended	0
What do you think an abnormal Pap smear most commonly means?	
Abnormal, precancerous cells	1
Cancer	0
Infection	0
Don't know	0
Which of the following might <u>increase</u> the risk of cervical cancer?	
Not using condoms	1
Being infected with human papillomavirus (HPV)	1
Starting sex at a young age	1
Smoking	1
Having genital warts	0
Stress	0
Having frequent sex	0
Having lots of sexual partners	1
A family history of cervical cancer	0
Not having regular Pap smears	1
Taking the oral contraceptive pill	1
Having many pregnancies/children	1
Being overweight	0
Poor hygiene	0
TOTAL	**13**

*HPV Knowledge Tool**

Item	Answer
A person may be infected with HPV and not know it	T
Those with HPV may need Pap smears more often	T
HPV is spread through sexual intercourse	T
The Pap smear is a test for HPV	F
HPV can cause problems with pregnancy	F
HPV can be cured with antibiotics	F
HPV causes women to have abnormal periods	F
If you have HPV, smoking can increase your chance of cervical cancer	T
Condoms do not always help protect you against HPV	T
Women can often clear HPV without treatment	T
Certain types of HPV cause cancer of the cervix	T
There is a vaccine to prevent some types of HPV	T
Highest Possible Score	**12**

* These items were only asked of respondents who had heard of HPV

Vaccination Attitude Scales

Vaccination in General

Item		**strongly agree**	**agree**	**uncertain**	**disagree**	**strongly disagree**
1	Prevention is better than cure for cervical cancer	**5**	**4**	**3**	**2**	**1**
2	Vaccines are an important way to prevent disease	**5**	**4**	**3**	**2**	**1**
3	Everyone should be vaccinated against preventable diseases in childhood	**5**	**4**	**3**	**2**	**1**
4	Vaccines that have been approved by the health department are safe	**5**	**4**	**3**	**2**	**1**
5	All children should be vaccinated against preventable conditions while they are still babies	**5**	**4**	**3**	**2**	**1**
6	The costs involved would influence my decision to have a child of mine vaccinated	**1**	**2**	**3**	**4**	**5**
7	The convenience of the venue where the vaccine is given would influence my decision to have a child of mine vaccinated	**1**	**2**	**3**	**4**	**5**
8	I worry about the side-effects of vaccines for children	**1**	**2**	**3**	**4**	**5**

HPV Vaccination Attitudes

Item		**strongly agree**	**agree**	**uncertain**	**disagree**	**strongly disagree**
1	If I had a 12 year old daughter, I would not want her to be vaccinated against HPV	**1**	**2**	**3**	**4**	**5**
2	Vaccinating young women and girls against HPV would encourage them to become sexually active	**1**	**2**	**3**	**4**	**5**
3	If I had a 12 year old daughter, I would need more information before I could decide whether she should be vaccinated against HPV	**1**	**2**	**3**	**4**	**5**
4	If I had a 12 year old daughter, and my doctor thinks it is a good idea, I would have her vaccinated against HPV	**5**	**4**	**3**	**2**	**1**
5	There is more risk involved in being vaccinated than in having HPV	**1**	**2**	**3**	**4**	**5**
6	The cervical cancer vaccine works best when it is given before a young woman becomes sexually active	**5**	**4**	**3**	**2**	**1**

The ratings above have been recorded in accordance with positive or negative statements. Positive responses (rated 5 or 4) were allocated a score of 1 for the purposes of analysis for each item and summed to give a total score (Pitts et al., 2007).

Appendix I
Variable Derivations

Variable	How collected in survey	Refinement/Construction Required
Age	Continuous	Converted from continuous to categorical 10 year age groups
Locality	Postcode of residence	Mapped to statistical local area (SLA) and then mapped to ASGC classifications – 5 categories. Further collapsed into 3 categories – metropolitan cities, inner regional and outer regional, remote and very remote.
SES	Postcode of residence converted to SEIFA categories by the CATI facility into deciles and quintiles of relative socio-disadvantage.	Quintiles used for analysis.
Education	Highest year of formal schooling completed (9 categories) Completion of further qualifications Highest qualification completed (8 categories)	Converted into educational status by transforming three variables. Highest year of schooling grouped to 2 categories, less than year 10 and greater than year 10. Highest qualification completed grouped into 2 categories, Bachelor Degree or Higher and Certificate/Diploma.
Marital status	8 categories	Converted to 4 categories – married; defacto; separated,/divorced/ widowed; never married
Australian-born	3 categories	Converted to dichotomous variable – yes/no
Indigenous status	3 categories	No change
Parity	3 categories	Converted to dichotomous – yes/no
Screening status	Length of time since last Pap smear (6 categories) Usual time between Pap smears (12 categories)	Converted into screening status by combining two variables - Length of time since last Pap & usual time between Paps – categorical – unscreened/underscreened/regularly screened/ overscreened/other
History of abnormal Pap smear	3 categories	Converted to dichotomous – yes/no
Smoking status	7 categories	Converted to dichotomous – current smoker- yes/no
Heard of HPV vaccine	4 categories	Converted to categorical dichotomous – yes/no
Where heard of HPV vaccine	Multiple responses	No change
Had HPV vaccine	4 categories	Converted to categorical dichotomous – yes/no
Heard of HPV	4 categories	Converted to categorical dichotomous – yes/no

Knowledge of cervical cancer/screening	Purpose (6 categories) Recommendations – Frequency, start screening, cease screening (7categories per item) What results mean (6 categories) Risks (12 items)	Risk factor items combined to form a score for this item and then combined with correct responses of other items to form a score then converted to above/below average levels Categorical to Continuous to Categorical
Knowledge of HPV	True /false items (12 items)	Correct responses compiled to form a score then converted to above/below average levels Categorical to Continuous to Categorical
Attitudes towards vaccination in general	Attitude scale	Positive responses compiled to form a score then converted to positive and negative attitudes Categorical to Continuous to Categorical
Attitudes towards HPV vaccine	Attitude scale	Positive responses compiled to form a score then converted to positive and negative attitudes Categorical to Continuous to Categorical

Appendix J
Multicollinearity Diagnostics

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	.551	.125		4.416	.000		
	Age in 10 yr groups	-.003	.014	-.009	-.245	.807	.841	1.189
	Locality	-.026	.022	-.039	-1.204	.229	.987	1.013
	SES	.003	.011	.009	.265	.791	.936	1.068
	Australian born	-.025	.043	-.019	-.590	.555	.962	1.039
	Educational attainment	-.004	.017	-.009	-.256	.798	.882	1.134
	Marital status	-.009	.021	-.015	-.445	.656	.928	1.077
	Had children	-.007	.042	-.006	-.173	.863	.845	1.183
	Smoking status	.041	.041	.034	1.006	.314	.946	1.058
	Screening status	.052	.029	.062	1.808	.071	.898	1.114
	Abnormal Pap history	-.027	.037	-.025	-.729	.466	.897	1.115

a. Dependent Variable: Cx screening knowledge level

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	.026	.116		.222	.824		
	Age in 10 yr groups	.009	.013	.024	.720	.472	.841	1.189
	Locality	.037	.020	.057	1.838	.066	.986	1.014
	SES	.013	.010	.041	1.298	.195	.936	1.068
	Australian born	.092	.040	.072	2.316	.021	.962	1.040
	Educational attainment	.084	.015	.179	5.482	.000	.881	1.134
	Marital status	-.006	.019	-.010	-.318	.750	.928	1.077
	Had children	-.037	.039	-.032	-.946	.344	.845	1.183
	Smoking status	.074	.038	.062	1.952	.051	.945	1.059
	Screening status	.035	.026	.042	1.305	.192	.895	1.118
	Abnormal Pap history	-.076	.034	-.073	-2.247	.025	.897	1.115
	Cx screening knowledge level	.221	.030	.227	7.374	.000	.991	1.009

a. Dependent Variable: Heard of HPV

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	.346	.172		2.012	.045		
	Age in 10 yr groups	-.037	.017	-.092	-2.173	.030	.844	1.185
	Locality	.020	.026	.030	.759	.448	.974	1.026
	SES	.011	.014	.032	.780	.436	.913	1.095
	Australian born	-.068	.054	-.051	-1.256	.210	.929	1.077
	Educational attainment	.027	.021	.054	1.309	.191	.882	1.134
	Marital status	-.045	.026	-.070	-1.743	.082	.940	1.064
	Had children	-.056	.049	-.048	-1.141	.254	.860	1.162
	Smoking status	.014	.053	.011	.265	.791	.927	1.079
	Screening status	-.001	.035	-.001	-.015	.988	.879	1.137
	Abnormal Pap history	-.082	.044	-.077	-1.848	.065	.860	1.163
	Cx screening knowledge level	.191	.041	.184	4.667	.000	.974	1.027
	Heard of HPV vaccine	.224	.074	.123	3.040	.002	.917	1.091
	General vaccine attitudes	-.025	.067	-.016	-.370	.711	.849	1.178
	HPV vaccine attitudes	.112	.053	.092	2.093	.037	.783	1.278

a. Dependent Variable: HPV knowledge level

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	.744	.084		8.881	.000		
	Age in 10 yr groups	-.021	.009	-.079	-2.313	.021	.841	1.189
	Locality	.003	.014	.007	.233	.816	.982	1.018
	SES	.009	.007	.039	1.213	.225	.935	1.070
	Australian born	.081	.029	.089	2.800	.005	.957	1.045
	Educational attainment	.017	.011	.050	1.494	.135	.854	1.171
	Marital status	-.002	.014	-.005	-.161	.872	.928	1.077
	Had children	-.020	.028	-.024	-.697	.486	.844	1.184
	Smoking status	-.003	.027	-.004	-.126	.900	.941	1.063
	Screening status	.008	.019	.014	.413	.679	.893	1.120
	Abnormal Pap history	-.086	.025	-.116	-3.504	.000	.892	1.121
	Cx screening knowledge level	.039	.022	.056	1.739	.082	.937	1.067
	Heard of HPV	.116	.023	.164	4.936	.000	.888	1.126

a. Dependent Variable: Heard of HPV vaccine

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Tolerance	VIF
1	(Constant)	.764	.086		8.912	.000		
	Age in 10 yr groups	.007	.009	.028	.799	.424	.836	1.196
	Locality	.020	.014	.047	1.434	.152	.982	1.018
	SES	.002	.007	.011	.338	.735	.933	1.072
	Australian born	.020	.028	.024	.714	.475	.949	1.054
	Educational attainment	-.004	.011	-.012	-.343	.732	.852	1.173
	Marital status	-.030	.014	-.074	-2.212	.027	.928	1.077
	Had children	.012	.028	.015	.440	.660	.844	1.185
	Smoking status	.048	.027	.059	1.781	.075	.941	1.063
	Screening status	.026	.019	.047	1.369	.171	.893	1.120
	Abnormal Pap history	.000	.024	.000	.010	.992	.881	1.136
	Cx screening knowledge level	.018	.022	.028	.842	.400	.934	1.071
	Heard of HPV	.022	.023	.033	.942	.346	.866	1.155
	Heard of HPV vaccine	-.018	.032	-.019	-.566	.571	.920	1.087

a. Dependent Variable: General vaccine attitudes

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Tolerance	VIF
1	(Constant)	.148	.111		1.331	.183		
	Age in 10 yr groups	-.011	.011	-.033	-1.014	.311	.835	1.197
	Locality	.023	.018	.040	1.309	.191	.980	1.020
	SES	.011	.009	.037	1.200	.230	.933	1.072
	Australian born	.095	.035	.083	2.686	.007	.948	1.055
	Educational attainment	.002	.014	.005	.169	.866	.852	1.174
	Marital status	-.005	.017	-.010	-.312	.755	.923	1.083
	Had children	-.013	.034	-.013	-.385	.700	.844	1.185
	Smoking status	-.010	.033	-.010	-.313	.755	.938	1.066
	Screening status	-.005	.023	-.007	-.231	.818	.892	1.120
	Abnormal Pap history	-.099	.030	-.105	-3.292	.001	.881	1.135
	Cx screening knowledge level	.096	.027	.109	3.517	.000	.934	1.071
	Heard of HPV	.036	.029	.040	1.240	.215	.864	1.157
	Heard of HPV vaccine	.221	.040	.174	5.557	.000	.919	1.088
	General vaccine attitudes	.346	.040	.258	8.545	.000	.981	1.019

a. Dependent Variable: HPV vaccine attitudes

Appendix K
Bivariate Results

Table K1. Bivariate Relationships between Cervical Cancer Screening Knowledge Levels and Socio-demographic and Screening History in a Community Sample of 1002[a] Women, Queensland, 2008

	Cervical Cancer/Screening Knowledge Levels					
	below average		above average			
	N (445)	% (44.6)	N (554)	% (55.4)	*X2* [b]	*P* [c]
SOCIO-DEMOGRAPHIC						
Age in 10 yr groups					0.46	0.98
20–29	111	44.5	138	55.5		
30–39	116	44.6	144	55.4		
40–49	105	45.6	125	54.4		
50–59	74	45.0	90	55.0		
60–69	40	41.4	56	58.6		
Locality					4.88	0.18
remote,very remote	16	53.6	14	46.4		
outer regional	95	42.5	129	57.5		
inner regional	145	49.0	151	51.0		
major cities	189	42.0	261	58.0		
Socioeconomic status					2.43	0.66
quintile 1 (most disadv)	76	43.0	100	57.0		
quintile 2	91	49.3	93	50.7		
quintile 3	66	43.6	86	56.4		
quintile 4	87	45.0	107	55.0		
quintile 5 (least disadv)	125	42.7	168	57.3		
Australian born					0.31	0.58
no	79	42.9	106	57.1		
yes	366	44.9	448	55.1		
Educational attainment					0.31	0.96
year 10 or below	80	45.7	95	54.3		
year 11or 12	76	43.8	97	56.2		
certificate or diploma	177	43.9	227	56.1		
Ba degree or higher	112	45.5	134	54.5		
Marital status					0.19	0.98
never married	64	45.4	77	54.6		
married	262	44.1	333	55.9		
defacto	76	45.4	91	54.6		
sep/div/wid	44	44.9	53	55.1		
Had children					0.01	0.93
no	109	44.8	134	55.2		
yes	337	44.5	420	55.5		
Smoking status					2.10	0.15
yes	101	49.2	105	50.8		
no	344	43.4	449	56.6		
SCREENING HISTORY						
Screening status [d]					6.66	0.04
underscreened	81	53.5	70	46.5		
regularly screened	266	42.6	358	57.4		
overscreened	76	41.2	108	58.8		
Abnormal Pap history					1.78	0.18
yes	121	41.4	172	58.6		
no	324	45.9	382	54.1		

[a] Weighted sample N = 999

[b] [c] Likelihood ratio - Chi square

[c] *p* = significance at p <0.05

[d] N=958 excludes women in the 'other' category

Table K2. Bivariate Relationships between HPV Awareness and Socio-demographic, Screening History and Knowledge in a Community Sample of 1002[a] Women, Queensland, 2008

	Awareness of HPV					
	No/Don't know		Yes			
	N (366)	% (36.6)	N (633)	% (63.4)	X^2	p
SOCIO-DEMOGRAPHIC						
Age in 10 yr groups					4.25	0.37
20–29	91	36.5	158	63.5		
30–39	95	36.5	165	63.5		
40–49	81	35.4	148	64.6		
50–59	55	33.5	109	66.5		
60–69	44	46.1	52	53.9		
Locality					3.77	0.15
outer reg, rem, vremote	101	39.7	153	60.3		
major cities	170	37.9	279	62.1		
inner reg	96	32.3	201	67.7		
Socioeconomic status					8.80	0.07
quintile 1 (most disadv)	68	38.7	108	61.3		
quintile 2	73	39.5	111	60.5		
quintile 3	67	43.9	85	56.1		
quintile 4	68	35.0	126	65.0		
quintile 5 (least disadv)	91	31.1	202	68.9		
Australian born					1.10	0.30
no	74	40.2	111	59.8		
yes	292	35.9	522	64.1		
Educational attainment					33.09	<0.0001
year 10 or below	88	50.4	87	49.6		
year 11or 12	73	42.2	100	57.8		
cert or diploma	146	36.2	258	63.8		
Ba degree or higher	60	24.2	187	75.8		
Marital status					4.47	0.21
never married	57	40.2	84	59.8		
married	203	34.1	392	65.9		
defacto	69	41.7	97	58.3		
sep/div/wid	38	38.8	59	61.2		
Had children					4.61	0.03
no	75	30.9	167	69.1		
yes	292	38.6	465	61.4		
Smoking status					7.75	0.01
yes	93	45.0	113	55.0		
no	274	34.5	519	65.5		
SCREENING HISTORY						
Screening status					7.87	0.02
underscreened	68	45.3	82	54.7		
regularly screened	229	36.8	394	63.2		
overscreened	56	30.6	128	69.4		
Abnormal Pap history					5.15	0.02
yes	92	31.3	201	68.7		
no	275	38.9	431	61.1		
KNOWLEDGE						
Cx screen kn level					55.86	<0.0001
below average	220	49.4	225	50.6		
above average	147	26.5	407	73.5		

[a] Weighted sample N = 999
[b] Likelihood Ratio – Chi square
[c] p = significance at p <0.05

Table K3. Bivariate Relationships between HPV Knowledge and Socio-demographic, Screening History and Knowledge in a Community Sample of 1002[a] Women, Queensland, 2008

	HPV kn level					
	below average		above average			
	N (278)	% 44.0	N (354)	% 56.0	X^{2b}	P^c
SOCIO-DEMOGRAPHIC						
Age in 10 yr groups					17.26	0.002
20–29	52	32.7	106	67.3		
30–39	72	43.7	93	56.3		
40–49	67	45.4	81	54.6		
50–59	55	50.1	54	49.9		
60–69	32	62.6	19	37.4		
Locality [d]					7.16	0.03
outer reg, rem, vremote	75	49.0	78	51.0		
major cities	106	38.0	173	62.0		
inner reg	97	48.3	104	51.7		
Socioeconomic status					7.14	0.13
quintile 1 (most disadv)	51	47.7	56	52.3		
quintile 2	54	48.9	57	51.1		
quintile 3	41	47.9	44	52.1		
quintile 4	58	46.2	68	53.8		
quintile 5 (least disadv)	74	36.4	129	63.6		
Australian born					0.69	0.41
no	45	40.3	66	59.7		
yes	234	44.8	288	55.2		
Educational attainment					7.50	0.06
year 10 or below	49	56.9	37	43.1		
year 11or 12	43	43.5	57	56.5		
cert or diploma	110	42.8	147	57.2		
Ba degree or higher	74	39.5	113	60.5		
Marital status					23.22	<0.0001
never married	18	21.4	66	78.6		
married	185	47.3	206	52.7		
defacto	48	49.7	49	50.3		
sep/div/wid	27	45.1	33	54.9		
Had children					10.24	0.001
no	56	33.5	111	66.5		
yes	222	47.8	243	52.2		
Smoking status					0.03	0.86
yes	51	44.7	63	55.3		
no	228	43.9	292	56.1		
CERVICAL SCREENING HISTORY						
Screening status					1.56	0.46
underscreened	34	41.8	48	58.2		
regularly screened	183	46.5	211	53.5		
overscreened	52	41.0	75	59.0		
Abnormal Pap history					3.88	0.05
yes	77	38.4	124	61.6		
no	201	46.6	230	53.4		
KNOWLEDGE AND AWARENESS						
Cx screen kn level					30.57	<0.0001
below average	132	58.6	93	41.4		
above average	146	35.9	261	64.1		
Heard of HPV vaccine					19.64	<0.0001
no	38	73.4	14	26.6		
yes	241	41.4	341	58.6		
ATTITUDES						

General vaccine attitudes					0.81	0.39
negative	33	48.8	34	51.2		
positive	246	43.4	320	56.6		
HPV vaccine attitudes					14.79	<0.0001
negative	80	58.7	57	41.3		
positive	198	39.9	298	60.1		

[a] N = 633 (weighted and excludes those who have not heard of HPV)
[b] Likelihood Ratio – Chi square
[c] *p* = significance at < 0.05
[d] outer regional, remote and very remote categories combined

Table K4. Bivariate Relationships between Awareness of the HPV Vaccine and Socio-demographic, Screening History and Knowledge Variables in a Community Sample of 1002 [a] Women, Queensland, 2008

	Heard HPV vaccine					
	No		**Yes**			
	N (137)	**% (13.7)**	**N (863)**	**% (86.3)**	**X^{2} [b]**	***P*** [c]
SOCIO-DEMOGRAPHIC						
Age in 10 yr groups					29.00	<0.0001
20–29	21	8.3	228	91.7		
30–39	46	17.6	214	82.4		
40–49	20	8.7	210	91.3		
50–59	23	14.0	141	86.0		
60–69	27	28.2	69	71.8		
Locality [d]					5.16	0.16
outer reg, rem, vremote	40	15.9	212	84.1		
major cities	53	11.8	397	88.2		
inner reg	43	14.6	254	85.4		
Socioeconomic status					4.60	0.33
quintile 1 (most disadv)	28	16.0	148	84.0		
quintile 2	28	15.3	156	84.7		
quintile 3	25	16.8	126	83.2		
quintile 4	22	11.4	172	88.6		
quintile 5 (least disadv)	33	11.1	261	88.9		
Australian born					7.01	0.01
no	37	20.0	148	80.0		
yes	100	12.2	715	87.8		
Educational attainment					8.27	0.04
year 10 or below	33	18.7	142	81.3		
year 11or 12	26	15.3	146	84.7		
cert or diploma	54	13.3	350	86.7		
Ba degree or higher	23	9.4	223	90.6		
Marital status					3.86	0.28
never married	19	13.7	122	86.3		
married	81	13.5	514	86.5		
defacto	18	10.8	149	89.2		
sep/div/wid	19	19.3	78	80.7		
Had children					4.22	0.04
no	24	9.7	219	90.3		
yes	113	14.9	644	85.1		
Smoking status					0.39	0.53
yes	31	15.0	175	85.0		
no	106	13.3	688	86.7		
CERVICAL SCREENING HISTORY						
Screening status					5.00	0.08
underscreened	26	17.0	125	83.0		
regularly screened	88	14.1	536	85.9		
overscreened	17	9.1	167	90.9		

Abnormal Pap history					18.58	<0.0001
yes	20	6.8	273	93.2		
no	117	16.5	590	83.5		
KNOWLEDGE AND AWARENESS						
Cx screen kn level					10.90	0.001
below average	79	17.7	367	82.3		
above average	58	10.4	496	89.6		
Heard of HPV					43.45	<0.0001
no	85	23.3	281	76.7		
yes	51	8.1	581	91.9		

[a] Weighted sample = 999
[b] Likelihood Chi square
[c] p = significance at < 0.05
[d] outer regional, remote and very remote categories combined

Table K4: Bivariate Relationships between General Vaccination Attitudes and other Factors in a Community Sample of 1002 [a] Women, Queensland, 2008

	General vaccination attitudes					
	negative		positive			
	N (117)	% (11.7)	N (882)	% (88.3)	X^{2} [b]	P [c]
SOCIO-DEMOGRAPHIC						
Age in 10 yr groups					4.68	0.32
20–29	29	11.7	220	88.3		
30–39	29	11.2	231	88.8		
40–49	33	14.3	197	85.7		
50–59	19	11.8	145	88.2		
60–69	6	6.7	89	93.3		
Locality [d]					2.69	0.26
outer reg, rem, vremote	37	14.6	216	85.4		
major cities	48	10.6	402	89.4		
inner reg	32	10.9	265	89.1		
SES					7.41	0.12
quintile 1 (most disadv)	21	11.7	155	88.3		
quintile 2	20	11.1	164	88.9		
quintile 3	20	13.2	132	86.8		
quintile 4	31	16.1	163	83.9		
quintile 5 (least disadv)	24	8.3	269	91.7		
Australian born					0.11	0.74
no	23	12.4	162	87.6		
yes	94	11.5	720	88.5		
Educational attainment					6.63	0.08
year 10 or below	23	13.4	151	86.6		
year 11or 12	11	6.6	161	93.4		
cert or diploma	53	13.2	351	86.8		
Ba degree or higher	29	11.8	217	88.2		
Marital status					6.38	0.09
never married	13	9.4	128	90.6		
married	62	10.5	532	89.5		
defacto	23	14.1	143	85.9		
sep/div/wid	18	18.3	79	81.7		
Had children					0.10	0.76
no	27	11.2	215	88.8		
yes	90	11.9	667	88.1		
Smoking status					4.35	0.04
yes	33	16.0	173	84.0		
no	84	10.6	709	89.4		
SCREENING HISTORY						
Screening status					5.73	0.06
underscreened	27	18.1	123	81.9		

regularly screened	66	10.6	557	89.4		
overscreened	22	11.7	163	88.3		
Abnormal Pap history					0.00	0.95
yes	34	11.6	259	88.4		
no	83	11.8	623	88.2		
KNOWLEDGE AND AWARENESS						
Cx screening knowledge level					0.95	0.33
below average	57	12.9	388	87.1		
above average	60	10.7	495	89.3		
Heard of HPV					2.02	0.16
no	50	13.5	317	86.5		
yes	67	10.6	565	89.4		
Heard of HPV vaccine					0.09	0.77
no	15	11.0	122	89.0		
yes	102	11.8	761	88.2		

[a] Weighted sample = 999
[b] Likelihood Chi square
[c] p = significance at < 0.05
[d] outer regional, remote and very remote categories combined

Table K5: Bivariate Relationships between HPV Vaccination Attitudes and other Factors in a Community Sample of 1002 [a] Women, Queensland, 2008

	HPV vaccination attitudes					
	negative		**positive**			
	N (260)	**% (26.0)**	**N (738)**	**% (74.0)**	**X^{2} [b]**	***P*** [c]
SOCIO-DEMOGRAPHIC						
Age in 10 yr groups						
20–29	57	22.9	192	77.1	5.55	0.24
30–39	70	26.8	191	73.2		
40–49	55	23.8	175	76.2		
50–59	46	28.1	118	71.9		
60–69	33	33.9	63	66.1		
Locality [d]					2.32	0.31
outer reg, rem, vremote	75	29.5	178	70.5		
major cities	110	24.5	339	75.5		
inner reg	75	25.3	222	74.7		
Socioeconomic status					17.56	0.002
quintile 1 (most disadv)	39	22.2	137	77.8		
quintile 2	62	33.7	122	66.3		
quintile 3	53	35.1	98	64.9		
quintile 4	42	21.4	152	78.6		
quintile 5 (least disadv)	64	21.8	229	78.2		
Australian born					12.78	<0.0001
no	68	36.5	117	63.5		
yes	192	23.6	621	76.4		
Educational attainment					3.43	0.33
year 10 or below	54	30.9	121	69.1		
year 11or 12	42	24.4	131	75.6		
cert or diploma	96	23.8	307	76.2		
Ba degree or higher	66	26.9	180	73.1		
Marital status					1.69	0.64
never married	33	23.4	108	76.6		
married	154	25.9	440	74.1		
defacto	43	25.9	124	74.1		
sep/div/wid	30	31.0	67	69.0		
Had children					1.34	0.25
no	56	23.3	186	76.7		
yes	203	26.9	553	73.1		

Smoking status					0.18	0.67
yes	56	27.3	150	72.7		
no	204	25.7	589	74.3		
CERVICAL SCREENING HISTORY						
Screening status					4.66	0.10
underscreened	49	32.2	102	67.8		
regularly screened	156	25.0	468	75.0		
overscreened	41	22.4	142	77.6		
Abnormal Pap history					19.15	<0.0001
yes	49	16.9	243	83.1		
no	210	29.8	496	70.2		
KNOWLEDGE AND AWARENESS						
Cx screen kn level					20.59	<0.0001
below average	147	33.1	297	66.9		
above average	113	20.3	441	79.7		
Heard HPV					16.80	<0.0001
no	123	33.6	243	66.4		
yes	137	21.7	495	78.3		
Heard HPV vaccine					46.25	<0.0001
no	70	50.9	67	49.1		
yes	190	22.1	671	77.9		
ATTITUDES						
General vaccination attitudes					58.97	<0.0001
negative	67	57.6	50	42.4		
positive	193	21.8	689	78.2		

[a] Weighted sample = 998
[b] Likelihood Chi square
[c] p = significance at < 0.05
[d] outer regional, remote and very remote categories combined

Appendix L
Focus Group Topic Guide

- INTRODUCE SELF, WELCOME, HOUSEKEEPING AND OUTLINE OF PROCESS
- CONSENT (WRITTEN) AND FOR RECORDING
- INTRODUCTIONS OF PARTICIPANTS

Today we are going to be talking about cervical cancer, screening for this cancer and the new vaccine that was developed to prevent cancer of the cervix. So firstly,

What do you think of the following statement: "Good health is largely a matter of good luck"
(self-efficacy – prompt to determine if women consider they are able to influence their own health)

What do you think causes cancer of the cervix?
(Perceived susceptibility to cervical cancer)

Do you think every woman has the same risk of getting cancer of the cervix?
(Perceived susceptibility to cervical cancer)

If a woman gets cervical cancer, is there a cure? Do you think it would have a big impact on a woman's health?
(Perceived seriousness of cervical cancer; belief that cervical cancer would have serious negative consequences on health and well-being)

What do you know about Pap smears? (what are they testing for, how often do you have them, when should women start and stop, how good are they at preventing cervical cancer)
(Perceived benefits of cervical screening, perception cervical screening decreases threat of disease)

What do you think prevents some women from having Pap smears or putting them off?
(Perceived barriers to cervical screening)

If there was a test you could do at home, say a tampon or swab you could insert yourself and send off in the mail, do you think women who don't go for Pap smears now might do it?
(Cues to action that may trigger one to participate in screening)

What do you know about human papillomavirus or HPV?
(Perceived susceptibility to HPV - knowledge of HPV and its link with cervical cancer)

What do you know about the new vaccine for preventing cancer of the cervix?

(Perceived benefits of HPV vaccination of school aged girls/self)

What do you think would prompt a woman to agree for her daughter to have the vaccine or to have the vaccine herself?
(Cues to action that may trigger one to participate in vaccination, or consent for child to be vaccinated)

Where do you get your health information from?
(Cues to action)

The QCSP has developed a number of ways to provide information about HPV and cervical cancer such as ads on TV, in magazines, brochures, posters and reminder letters. If there was new information we wanted to provide to women - what do you think is a good way to do this?
(Cues to action)

SUMMARY (points to cover):

Today's session has been very beneficial in assisting our Program to gain a better understanding of what women know about cervical cancer, HPV, Pap smears and the new vaccine. Thank you to everyone who participated today. As mentioned earlier, no original names will be used in any of the reports or documents produced from today's group.

If you would like feedback about the focus groups or more information about what we talked about today, please refer to the brochures and information we have for you. There is also information about who to contact if you want to discuss the focus group or research project further.

I have a list here where you can write your contact details if you would like a copy of the research findings from this project, although this will not be ready until early next year.

We have a small thank-you gift on the table for each of you and again thank-you for participating in today's focus group.

Appendix M
Focus Group Participant Questionnaire

The following questions are to assist the researcher to describe the characteristics of the group. No identifying information is required on this form. You do not have to answer any question if you would prefer not to.

Q1. Can you please tell me your age at your last birthday?

☐☐ years

If you are less than 20 years of age or over 70 years of age please come and see the researcher now. You should also see the researcher if you have had a hysterectomy.

Q2. What is your current marital status? Are you…..

Married ☐
De facto ☐
Separated ☐
Divorced ☐
Widowed ☐
Never married ☐
Don't know ☐

Q3. What is the highest level of primary or high school that you have completed?

Never attended school ☐
Currently still at school ☐
Year 8 or below (age 12–13 years or less) ☐
Year 9 or equivalent (age 13–14 years) ☐
Year 10 or equivalent (age 14–15 years / Junior) ☐
Year 11 or equivalent (age 15–16 years) ☐
Year 12 or equivalent (age 16–17 years / Senior) ☐
Don't know ☐

Q4. Have you completed any qualifications since completing school?

YES ☐
NO ☐
Don't know ☐

If yes, what is the highest qualification you have completed?

Bachelor degree or higher ☐
Trade Certificate (4 years duration) ☐
Diploma or Certificate (taking 12 months or more full time) ☐
Diploma or Certificate (taking less than 12 months full time) ☐
Other: please specify …….. ☐

Q 5. Were you born in Australia?

YES ☐ NO ☐ **(please go to Question 7 now)**

Q 6. Are you of Aboriginal or Torres Strait Islander origin?

YES ☐
NO ☐

Please go to Question 8 now.

Q 7. If you were not born in Australia, in which country were you born?

United Kingdom & Ireland ☐ New Zealand & Oceania ☐
Other (please state) ☐_____

Q 8. Do you have any children?

YES ☐ NO ☐

If yes, how many children have you given birth to? _____

Q9. How many times have you had a Pap smear test?

NEVER	☐	**(**please go to **QUESTION 12** now)			
ONCE	☐	(please go to **QUESTION 11** now)			
TWICE	☐	3–5 TIMES	☐	6–10 TIMES	☐
11–20 TIMES	☐	>20 TIMES	☐	Don't know	☐

Q 10. What is the usual time between your Pap smear tests?

Less than 1 year	☐	1 year	☐
18 months	☐	2 years	☐
3 years	☐	4 years	☐
5 years or more	☐	Don't know	☐

Q 11. When did you last have a Pap smear?

Less than 1 year ago	☐
1 year to less than 2 years ago	☐
2 years to less than 3 years ago	☐
3 years to less than 5 years ago	☐
5 or more years ago	☐
Don't know	☐

Q 12. Have you heard of HPV?

YES	☐
NO	☐

Q13. Have you heard of the vaccine for cervical cancer or HPV?

YES	☐
NO	☐

Q 14. So that we can establish the boundaries of our interviewing area, can I ask what is your suburb, town or community?

Brisbane	☐
Cairns	☐
Gold Coast	☐
Ipswich	☐

Logan ☐
Mackay ☐
Redcliffe ☐
Redlands ☐
Rockhampton ☐
Sunshine Coast ☐
Toowoomba ☐
Townsville ☐
Other (please state) ☐_____

Q15. Which suburb do you live in?

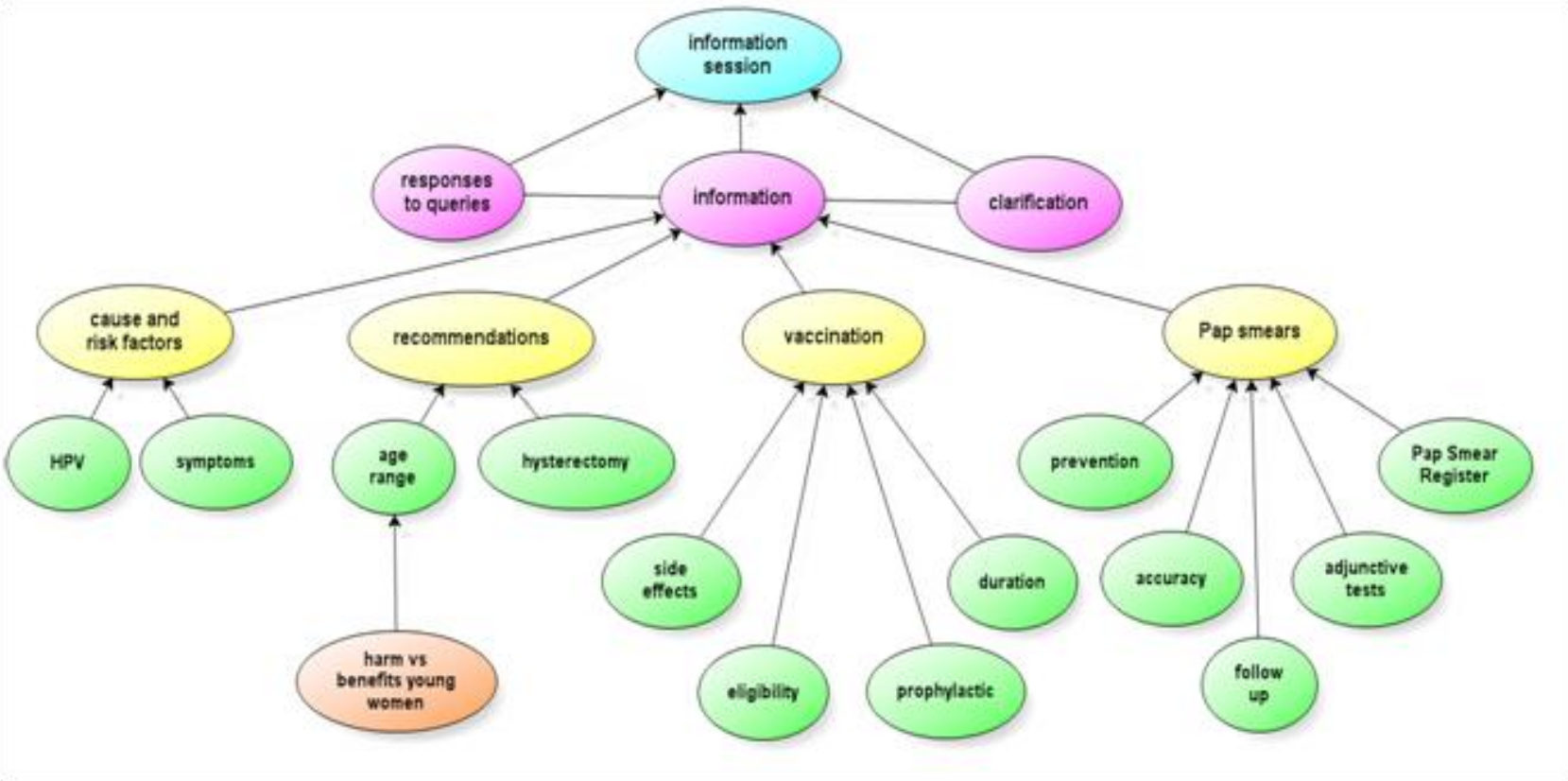
……..

Q 16. What is the postcode of your residence?

☐☐☐☐

There are no further questions. Thank you for completing this information. Would you please return this form to the researcher.

Appendix N
Topics Covered in Information Sessions Post Focus Groups



Appendix O
Personal Reflections from Phase 2

When I reflect on Phase 2 of the study, the processes I used for recruitment were very effective although I needed to be very proactive to get the involvement of women from more remote areas and approached more than one organisation to achieve this. Despite specifying the ideal size of a focus group was eight to 12, there was a wide variation from this range with some groups of only five or six participants and others with over 20 or more women (Figure 7.1).

There was only one group that did not eventuate which was due to it being included as part of a major community women's health expo and a high profile speaker scheduled to speak at the same time as the proposed focus group. In addition, a major weather event, a cyclone was looming at sea. I learnt a lot from this as it was the fourth group scheduled and was more proactive in obtaining in-depth details about planned events after reflecting on my preparation.

However I did not have much control over the number of women attending and ill health, funerals and women's enthusiasm to attend (often positive), were the unknowns that impacted on focus group numbers.

The preliminary activities prior to the focus groups getting underway were not always straight-forward. On a couple of occasions, the consent to participate was an issue for some women as described in section 3.3.2. Another preliminary issue related to protocol and the situation in which the focus group was held. Protocols differed according to the organisation and the event and I needed to be flexible and patient. When the event was held as part of a formal meeting such as those often held with QCWA and Zonta groups, there was sometimes a specified protocol which I learnt to enquire about before commencing. At times I was formally introduced or formally welcomed at a particular point in the meeting agenda by a senior person and on one occasion had to introduce myself and the project to a room of over 200 women at a regional event. At women's health events, I was provided a space, which at times was not optimal due to noise, and the organisers then directed women to the table or room.

When formal meetings occurred with dinner, we either conducted the focus group during the meal when formal proceedings had occurred or after the meal. At

other times, the process was very informal and it was handed over to me to run the show which when at women's homes felt a bit like a Tupperware party! These differing processes were important to follow as joining women for a meal or morning tea and often helping with preparations and cleaning up aided my acceptance and helped me feel I was contributing too. It did however, often make it a long day and this combined with travel was often a challenge.

The actual process of the focus groups worked well and I found by providing women with information about my role and my experience as a women's health nurse they trusted me to provide them with accurate information and I was a trusted source of knowledge. My perception was they viewed my role not only as a researcher but as someone with influence given the outcomes of the focus groups were to inform the work I coordinate.

The dynamics of focus groups is described from my reflective personal journal, from observer notes recorded at the time of the session and reflections when transcribing the recordings. Group dynamics differed between groups and I drew on all my facilitation skills especially when groups were large. I frequently used paraphrasing and reflecting to ensure I was interpreting women's meanings correctly and verify their intent. I tried to ensure all women participating had the opportunity to contribute and achieved this by directly asking women questions as they wore name tags. At times there were very vocal and dominant women in groups, however I asked women to wear name tags and would directly seek the views of other women to ensure more reserved women had the opportunity to contribute. I also sought the assistance of organisers for the very large groups and on one occasion co-opted a very vocal young woman as 'crowd control'. Their role was to remind women to speak one at a time and was arranged and agreed to prior to commencement of discussions.

Observer's notes reinforced my perception that groups were facilitated effectively:

- *Good participation from all.*
- *Leane good at managing participation from quieter participants.*
- *Liked the way she repeated answers for the whole group to digest..*
- *Asked quieter people to contribute.*
- *Women where all heard & listening.*

Humour featured highly in the majority of focus groups and words associated with laughter appear in the transcriptions 332 times. Women seemed to enjoy participating and as they were often friends or members that met regularly were comfortable with each other and often joked particularly when Pap smears and barriers to screening were being discussed. They were very open and this was reflected in my journal, observer notes and on listening to the tapes when at times it was difficult to hear what was being said due to laughter:

- *[People laughed a lot during this discussion]*
- *Gorgeous open bunch of women!*
- *I used to think it was once a year until you told me it was every two years and I was being ripped off by my gynaecologist! (lots of laughter)*
- *Lots of laughter and joking (inaudible)*
- *Participant 1: Our doctor used to send a letter on your birthday and Happy Birthday X, - it's that time.(laughter). I thought that's one way a woman would always remember.*
- *Participant 2: Did you have it with a candle? (laughter).*

I felt immensely privileged to have been so welcomed and accepted by the organisations and women in the groups and in turn they thanked me for coming to speak with them. It was good to be part of something that was mutually beneficial and I reflected often about this in my journal:

- *They thanked me at the end and expressed how much they enjoyed it which was lovely.*
- *Got email letter from group asking who could send a donation to for Cervical Ca research – I suggested xx. How lovely!*
- *Lots of positive feedback from women following the group.*
- *Got email later, thanking for attendance and saying how much women enjoyed it.*
- *Thoroughly enjoyed the session and we were given a QCWA cookbook each!*
- *They gave me an Anniversary mug which was very special.*
- *Women loved the thank you gift.*
- *They also were pleased I came to them - I wish I could go more remote but how long is a piece of string?*

There were a number of challenges in conducting the focus groups. These related to distractions and this was often related to the venue or event at which the focus group was held. As an invited guest I had little control over the venue or the meetings I was invited to despite providing information beforehand and speaking with the organisers about needing a quite space. At one focus group a play group was also in progress with the mothers participating which at times was disruptive and it was very difficult to hear women and transcribe the recordings due to noise. This was also the case at a women's health day as a designated room was not provided and other activities were underway in the same room which at times were noisy.

Dinner meetings were also a challenge with noise again a factor and the configuration of the room although at one event the younger women rearranged the room after the meal.

Other distractions related to women arriving after the focus group had commenced or were noise related such as children, dogs barking or passing trains. Heavy rain also caused pauses in discussions as the sound on the tin roofs in two remote communities was deafening and women could not hear each other so we paused and listened with joy to the breaking of the drought!

- *Dog barking- inaudible*
- *(inaudible – baby in the background)*
- *Crows caw (inaudible)*
- *(inaudible) due to rain.*

Taping also led to some distractions with the tape recorder turning off at times or the cassette running out. I used two recorders and became pretty adept at changing tapes quickly whilst talking but it still caused some issues. The other technical issue was the digital recorder I specifically purchased for recording the focus groups. Despite specifying what I needed it for, I was sold an inadequate recorder which meant I was not able to have the tapes transcribed by a transcription service. Although this caused a delay in my timelines as I had to transcribe the majority of tapes myself, it also enabled me to re-immerse myself in the data as a number of months had passed between conducting the focus groups and final analysis. I used two recorders and was able to hear most recordings albeit it a slow process at times! The recorders used did not assist in reducing the impact of background noise but it was rare not to capture what women said and the majority of tapes were reasonable with only seven requiring intensive work to successfully transcribe. There was one group however where not all the information was recorded due to technical issues with both recorders however this was at a site where two groups were held and the majority of the discussion was taped. There were consistent themes identified across groups and I therefore did not think there was a great impact on data quality by these issues given the number of groups that were conducted.

The other challenge was personal and related to me as the facilitator. I was working full-time, travelling a lot and was quite unwell at times, however I did not

cancel any bookings and managed to conduct a total of 23 focus groups over a nine month period due to the support of the participants, their organisations, my work colleagues and family.

In summary, the dynamics of these focus groups was positive and the women participating, myself and those observing appeared to enjoy the process and the experience. I remain in awe of the way I was welcomed by the organisations and women who attended the groups and had the pleasure of being at an event attended by a number of women from previous focus groups. They came up and introduced themselves and reinforced how much they had enjoyed being part of the research.

Despite the logistics and hard work involved in conducting so many focus groups, each group had something to offer and I enjoyed listening to the tapes and transcribing the recordings and at times laughed until I cried! I will never forget this experience and the wonderful information women shared with me to inform this project and future activities in my professional undertakings.

Appendix P
Acknowledgement of Role

I acknowledge my role in the qualitative phase of this study by using the pronoun 'I' in qualitative research reporting, asserting that my own experiences and view of the world have influenced my interpretation of data and that the findings of the focus groups do not represent 'truth' but are the views and experiences of the women involved and how I interpreted them. I also acknowledge my previous experience and professional role and agenda in conducting this research. I grew up in the southern Bayside suburbs of Brisbane and began nursing at the age of 17 at the Royal Brisbane Hospital when nursing education was hospital-based. My nursing experience at this large metropolitan hospital was primarily medical, surgical and oncology nursing and after completing my midwifery training on the same campus and having two children, I started working in the gynaecology-oncology unit in 1999. At the time, women from all over Queensland were sent to this unit where as a senior nurse, I primarily cared for women post-operatively with cervical, ovarian, endometrial, vulval and other gynaecological cancers.

Also during this time, I completed a nursing degree and this experience expanded my view of health beyond the bio-medical model. I became restless in the acute health sector and was successful in securing a position in the primary health care sector at Family Planning Queensland as the state-wide Nursing Services Manager. In this position, I was instrumental in the expansion of the scope of practice of registered nurses in the organisation to enable them to become Pap smear providers and provide contraceptive services for women such as emergency contraception and ongoing oral contraception under health management protocols. Given my experience caring for women dying from cervical cancer, I felt this would help increase women's access to female Pap smear providers and with the support of the FPQ education section, we began training nurses from other organisations, including Queensland Health, in these skills. I also completed a Master of Nursing during this time in which I focused on the acceptance of registered nurses as Pap smear providers and majored in women's health (Christie, Gamble and Creedy, 2005).

After seven years, it was time for a challenge and I then spent three years in roles as a manager of school-based nurses and a regional sexual health coordinator; however, I did not have the same passion for these roles as my previous positions that had women's health as the primary focus. Fortuitously a position became available in 2003 in the Queensland Cervical Screening Program which led to my current role as Program Director. In this role, my focus is the prevention of cervical cancer and the promotion of women's participation in the program. My experience and educational preparation, including studies in feminism and post-structuralism, cause me to challenge the language we use in our resources, for example, nurses and doctors do not 'take' Pap smears, they 'provide' them, and led me to this study where I hope to gain a greater understanding about women's knowledge, attitudes and the barriers they experience to regular participation in the program as I am in a position to make a difference.

I would like to make clear my rationale and intent for the use of value-laden language in this thesis such as 'promiscuity' and 'compliance'. I have used these terms to describe what women said or to reflect community perceptions when using the term 'promiscuity' and this does not reflect my personal view that sexual behaviour should be judged in this way as this is not my role nor my intent given the stigma and gender-specific labels frequently used to describe women's sexuality (Braun and Gavey, 1999). I also dislike the word 'compliance' as this for me has connotations of the 'good' versus the 'bad' patient and is paternalistic; however I have used this term when women spoke about having Pap smears or the vaccine because they were told to, rather than through a process of informed consent.

I acknowledge I have never lived or worked in rural and remote Queensland but I have travelled extensively by car through these areas and have seen the tyranny of distance where you may pass only a few vehicles in a whole day. This was why I felt it was so important to survey these women and go to these areas to talk with women face-to-face. I also acknowledge I am deeply passionate about this topic because this cancer can be prevented and although it was such a long time ago, having cared for women who suffer a horrendous death from cervical cancer, if this research and my role can help reduce cervical cancer even further than the gains to date, I have done what I set out to do.

As described by Liamputtong and Ezzy (2005), the opportunity to conduct this research was a privilege and I have made every attempt to deal with participants and their contributions to this process with honesty, integrity and fairness. I provided the women who expressed the desire to receive it, a summary report of the findings from the focus groups and have offered to present at their meetings and conferences in the future so I can share the findings with them and complete the research cycle (Appendix F).

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Appendix Q
Call Analysis

Table Q1: Final Call Result

	Total
Not connected Telstra message	7363
Appoint	1369
Business	1049
Complete	1002
Called 5 times without contact	471
Engaged	65
No women aged 20–69	2454
Respondent has had Hysterectomy	276
Respondent away duration	309
Not in survey area	3
Deaf / Drunk / Senile	69
Language	100
No answer	4769
Refused	1123
Quota full	274
Total	20696

Table Q2: Total attempts

	Total
Not connected Telstra message	7363
Appointments / answering machines	9227
Business	1049
Complete	1002
Called 5 times without contact	471
No women aged 20–69	2454
Respondent has had Hysterectomy	276
Respondent away duration	309
Not in survey area	3
Deaf / Drunk / Senile	69
Language	100
No answer / engaged	13842
Refused	1123
Quota full	274
Total Attempts	37562